

Department of Health and Human Services

**OFFICE OF
INSPECTOR GENERAL**

"KNOW YOUR NUMBER" BROCHURE

EXPERIENCES OF DIALYSIS FACILITIES



**JUNE GIBBS BROWN
Inspector General**

**JANUARY 1997
OEI-06-95-00321**

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EXECUTIVE SUMMARY

PURPOSE

This study describes the experiences of renal dialysis facilities in using the Health Care Financing Administration's (HCFA) "Know Your Number" brochure to educate end stage renal disease (ESRD) patients on how to monitor the adequacy of their dialysis treatment.

BACKGROUND AND METHODOLOGY

By Medicare's definition, ESRD is "that stage of renal impairment that appears irreversible and permanent, and requires a regular course of dialysis or kidney transplantation to maintain life." Concern has grown over the adequacy of hemodialysis with the recent release of the ESRD Core Indicators Workgroup's report, conducted as part of HCFA's and the 18 contracting ESRD Network Organization's quality assurance and continuous improvement efforts. This report found that only 43 percent of patients were receiving adequate hemodialysis.

The ESRD brochure "Know Your Number" was developed out of this concern. Its purpose is to educate the approximately 156,000 in-center hemodialysis patients so they may better determine the adequacy of their treatment and become more proactive in the treatment process. To ascertain the experience with and obtain the perspectives of facilities' staff regarding the brochure, we randomly surveyed 132 facilities treating hemodialysis patients.

FINDINGS

Facilities who received the brochure overwhelmingly reported the brochure includes useful information and most said it is somewhat or very easy for patients to understand. These facilities said the brochure allows staff to help patients become actively involved in their own dialysis, encourages patient compliance with their recommended treatment, and its' content is sometimes being used or will be used in facilities' educational outreach materials.

However, 22 percent of facilities reported not receiving the brochure. Some who got it, didn't fully disseminate it to patients. Furthermore, we found 21 percent of facilities do not calculate patients' URR or KT/V numbers on a monthly basis. Facilities calculating these numbers on a monthly basis were much more likely to also distribute the brochure and have patients who participate more proactively in their dialysis. This finding clearly highlights an important interaction between facility practice and the effectiveness of the brochure.

DISSEMINATION

Seventy six percent of facilities reported receiving the brochure, 22 percent said they did not. All but 13 percent of receiving facilities distributed the brochure, half to every patient and half to an average of 69 percent of their patients. Brochures were frequently (74 percent) personally handed to patients, often accompanied by an explanation from a registered nurse (84 percent).

Facilities not fully distributing the brochure said many patients wouldn't understand the brochure's content or they didn't receive enough brochures to distribute it more extensively. Facilities distributing the brochure most commonly handed the brochure to patients and/or placed it somewhere accessible in their facilities.

Registered nurses provided the majority of brochure explanations, with almost all facilities saying at least half or more of their patients appeared alert during their explanations.

BROCHURE'S EFFECTIVENESS

Seventy-two percent of facilities rated the brochure's effectiveness as a patient educational tool as either excellent or good, and 66 percent said the brochure was somewhat, or very, easy for their patients to understand.

Forty-six percent of facilities reported most or all of their patients wanted to know their own URR or KT/V number after receiving the brochure, and 47 percent said half or more of their patients asked questions about the brochure's content.

Almost all facilities (98 percent) said patients need to know the information in the brochure. Eighty-two percent said a brochure was an appropriate method for communicating this information.

DIALYSIS ADEQUACY

Facilities said at least 50 percent of their patients are interested in the adequacy of their dialysis, with 29 percent tracking their numbers month-to-month.

Clearly, the brochure's effectiveness cannot be assessed without considering facilities' practices, and in the process of conducting our study, we found not all facilities calculate dialysis adequacy measures on a monthly basis or routinely share them with their patients.

Only 77 percent of facilities calculate patients' numbers at least monthly, with 21 percent doing this only quarterly. Further, only 53 percent of facilities give patients their numbers all the time; many do so far less, 16 percent do this less than half the time.

Facilities who give patients their numbers monthly, or more often, were much more likely to have distributed the brochure to every patient and to have patients who track their numbers.

RECOMMENDATIONS

Overall, we found the brochure has the potential to serve as an effective part of a broader strategy of improving patients' understanding of adequate dialysis and enlisting their support in monitoring the adequacy of their dialysis. The "Know Your Number" brochure was given a positive assessment by facilities receiving it. However, the brochure was not received by all facilities nor was it fully distributed or explained to all patients by all receiving facilities.

It seems clear that the brochure's effectiveness in educating patients and involving them in monitoring dialysis still is heavily dependent upon facility practices and the quality of staff-patient relationships.

Based on our findings, we recommend that HCFA take the following actions to improve kidney dialysis:

DISSEMINATION. Assure all facilities receive an ample supply of brochures and encourage them to distribute a brochure to every patient. HCFA might also consider providing guidelines to facilities on effective dissemination approaches.

BROCHURE CONTENT & FORMAT. Simplify the language and concepts as much as possible in any subsequent or revised patient brochures. Consideration might be given to developing alternate versions of the brochure for different reading levels, and to adding greater use of color and graphics to gain interest and promote patient understanding.

CONTINUING PATIENT EDUCATION. Encourage continuing efforts by facilities to educate patients and to reinforce the importance of patient understanding and monitoring of the adequacy of their dialysis. A training video to introduce and/or reinforce the brochure concepts might also prove effective, based on the suggestions and experiences of some facilities.

USE OF ADEQUACY MEASURES. Encourage facilities to calculate dialysis adequacy measures on a monthly basis and to share these numbers with patients on a regular basis, in order for the brochure to achieve its intended impact on patients and facilities.

Additional Office of Inspector General Work

A companion report by the Inspector General's office (OEI-06-95-00320) provides information about perspectives of dialysis patients regarding the "Know Your Number" brochure. The report describes how successful the brochure was in increasing patient awareness of information about adequate dialysis, how it is measured, how patients know if they have achieved it, and what they can do to improve their dialysis. Additionally, it highlights how the brochure has helped enhance the dialogue between facilities and patients about adequate dialysis and the use of URR or KT/V numbers to monitor adequacy of dialysis treatment. The report also addresses problems with brochure dissemination, lack of patient familiarity with dialysis tests used by their facility and with target numbers indicating dialysis adequacy, even among patients receiving the brochure.

AGENCY COMMENTS

The Health Care Financing Administration (HCFA) concurred with all the report's recommendations. We appreciate their responsiveness to our proposals. However, we have a new concern that has arisen since we issued our draft report.

We originally recommended that HCFA encourage facilities to calculate dialysis adequacy monthly and share these numbers with patients on a regular basis. HCFA informed us that they had no requirement for facilities to measure the adequacy of dialysis at prescribed intervals but that their revised ESRD Conditions for Coverage will require facilities to calculate the adequacy of dialysis quarterly. This is in marked contrast to the upcoming National Kidney Foundation's Dialysis Outcome Quality Initiative guidelines which recommend a standard practice guideline of a monthly URR or KT/V calculation, not quarterly calculations. We are concerned that facilities will interpret HCFA's Conditions for Coverage as the acceptable standard and conduct adequacy testing only quarterly.

In our view, this could pose a severe health risk for ESRD patients whose dialysis could go three months before needed corrections could be made to their treatment. We are convinced that facilities should be required to calculate adequacy numbers monthly and we urge HCFA to reconsider or amend the Conditions for Coverage accordingly.

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INTRODUCTION

PURPOSE

This study describes the experiences of renal dialysis facilities in using the Health Care Financing Administration's (HCFA) "Know Your Number" brochure to educate end stage renal disease (ESRD) patients on how to monitor the adequacy of their dialysis treatment.

BACKGROUND

By Medicare's definition, ESRD is "that stage of renal impairment that appears irreversible and permanent, and requires a regular course of dialysis or kidney transplantation to maintain life."¹ Although some Americans with chronic kidney failure receive kidney transplants, the majority receive either hemodialysis or peritoneal dialysis treatment.^{2,3} Over 186,000 ESRD patients currently receive some form of dialysis therapy in the United States. Although dialysis is expensive and is not a cure, the treatments can greatly prolong an ESRD patient's life.

As a result of the Social Security Amendments of 1972 (P.L. 92-603), ESRD patients may qualify for Medicare under the renal disease provision which pays for 80 percent of the cost of the treatment no matter how old they are. To qualify for Medicare a person must: 1) have worked long enough to be insured under the Social Security program, or be the spouse/child of someone who has; or 2) already be receiving Social Security benefits. If a person isn't eligible for Medicare, they may qualify for Medicaid if their income is below a certain level.

To conduct oversight activities assuring the appropriateness of services for ESRD patients, Congress passed the ESRD Amendments of 1978 (P.L. 95-292) authorizing the establishment of ESRD Network Organizations. Currently, the Health Care Finance Administration contracts with 18 ESRD Network Organizations throughout the United States. In striving for quality assurance and continuous improvement, the ESRD Networks, together with HCFA and the renal community, worked to implement the ESRD Health Care Quality Improvement Program. This program allows the ESRD Networks and HCFA to track improvements in health care provided to renal Medicare beneficiaries through the development of quality indicators.

ESRD Core Indicators Project

In 1994 the ESRD Health Care Quality Improvement Program conducted the National/Network ESRD Core Indicators Project to assist providers of ESRD services in assessing and improving the care provided to ESRD patients. The first phase of this project targeted adult in-center hemodialysis patients receiving care in the last quarter of 1993. The project's focus was on establishing a consistent clinical database of key components of care. Such clinical measures included the determination of the adequacy of dialysis using the pre- and post-dialysis blood urea nitrogen (BUN) levels to calculate the urea reduction ratios

(URR).⁴ Baseline estimates were then used to identify opportunities for improvement in ESRD care across the United States.

The project's data was compared to standard medical levels of adequate hemodialysis developed by the Renal Physicians Association and a National Institute of Health (NIH) Consensus Development Conference Panel ($URR \geq 0.65$ or $KT/V \geq 1.2$).^{5,6,7} Only 43 percent of the study's patients met these new standards, with significant differences existing by gender, race, age, and region. The percent of patients in particular Network areas who received adequate hemodialysis ranged from 29 to 57 percent, accounting for differences by race and gender.

The ESRD Core Indicators Workgroup produced a report in late 1994, along with an analysis of the project's results, and is currently conducting an evaluation of the impact of the Health Care Quality Improvement Program on patient care and outcomes. Networks will also prepare summary reports of their intervention and follow-up activities on an annual basis.

ESRD Brochure

The ESRD brochure "Know Your Number" was developed out of concern for the large percent of hemodialysis patients not receiving adequate treatment. With the development of a consensus medical standard for adequate hemodialysis, patients now have a benchmark against which to compare their own test results.

The brochure's purpose is to educate the approximately 156,000 in-center hemodialysis patients so they may better determine the adequacy of their treatment and become more proactive in the treatment process. The brochure focuses on heightening patients' awareness of the following: 1) there is a recommended level of dialysis associated with a number; 2) why achieving this level is important; and 3) how patients would know if the recommended level of dialysis was achieved. The brochure also seeks to inform patients on what they can do to track and improve their dialysis test results.

A total of 350,000 brochures were initially printed in English, with an additional 50,000 brochures printed in Spanish for a later distribution. The brochures were sent directly to approximately 2,500 dialysis facilities for dissemination to ESRD patients. Distribution of the brochure to patients at the facility-level is intended to improve communication between providers and patients, in addition to increasing patients' understanding of their treatment and progress.

SCOPE

Since the goal of the ESRD "Know Your Number" brochure is to increase patient awareness about the adequacy of their dialysis, this study examined whether patients received the brochure and understood its content and also facilities' experience in using the brochure. In addition, we determined how brochures were disseminated and the extent of interaction between patients and providers as a result of the brochure's distribution. We did not aim to

measure any broad-based behavior changes by patients resulting from the brochure due to the difficulty of making such causal inferences.

METHODOLOGY

Sample selection

Using the HCFA's Medical Information System (PMMIS) database, we used simple random sampling to obtain two separate samples of 800 hemodialysis patients each in late October 1995 and mid-February 1996, testing both early and later dissemination of the brochure. The findings from this survey will be included in a separate OIG report (OEI-06-95-00321).

Using HCFA's Online Survey Certification and Reporting System (OSCAR) and Medical Information System (PMMIS) databases, we used simple random sampling to obtain a sample of 150 dialysis facilities in operation prior to October 1995. We surveyed the 132 facilities with hemodialysis patients in April 1996. Our response rate for this sample was 86 percent, with 113 facilities responding to our survey. Four additional completed surveys came in several months after the survey deadline and were not analyzed for this report.

An analysis of non-respondents versus respondents, based on key facility characteristics, such as ownership type, location of facility, number of hemodialysis stations, and the number of years with Medicaid/Medicare certification, showed no differences between the two groups.

A profile of responding facilities and facility staff completing our survey is provided in Appendix A. Confidence intervals for specific frequency estimates are provided in Appendix B.

This inspection was conducted in accordance with the *Quality Standards for Inspections* issued by the President's Council on Integrity and Efficiency.

FINDINGS

Facilities who received the brochure overwhelmingly reported the brochure includes useful information, and most said it is somewhat, or very, easy for patients to understand. These facilities said the brochure allows staff to help patients become actively involved in their own dialysis, encourages dialysis time compliance among patients, and its' content is sometimes being used, or will be used, in facilities' educational outreach materials.

However, 22 percent of facilities reported not receiving the brochure. Some who got it, didn't fully disseminate it to patients. Furthermore, we found 21 percent of facilities do not calculate patients' URR or KT/V numbers on a monthly basis. Facilities calculating these adequacy numbers on a monthly basis, were much more likely to also distribute the brochure and have patients who participate more proactively in their dialysis. This finding clearly highlights that there is an important interaction between facility practice and the effectiveness of the brochure.

DISSEMINATION

Seventy six percent of facilities reported receiving the brochure, although 22 percent said they did not. All but 13 percent of receiving facilities distributed the brochure, half to every patient and half to an average of 69 percent of their patients. Brochures were frequently (74 percent) personally handed to patients, often accompanied by an explanation from a registered nurse (84 percent).

A large majority (76 percent) of facilities reported receiving the brochure, while 22 percent said they did not receive it and another two percent did not remember receiving it. There were significant differences in facilities receiving the brochure based on facility location and type. Ninety-three percent of rural facilities reported receiving the brochure compared to only 81 and 64 percent of suburban and urban facilities (see table 1).

Table 1: FACILITIES RECEIVING BROCHURE			
by location of facility			
	Urban area	Suburban area	Rural area
Yes	64 % (30)	81 % (25)	93 % (28)
No/Didn't Remember	36 % (17)	19 % (6)	7 % (2)

Additionally, facilities attached to hospitals were more likely (88 vs. 72 percent) to have received the brochure than free-standing facilities (see table 2). However, there were no differences in the brochure's distribution based on the size of the facility or the number of patients treated.

Table 2: FACILITIES RECEIVING BROCHURE by type of facility		
	Free-standing	Attached to hospital
Yes	72% (54)	88% (30)
No/Didn't Remember	28% (21)	12% (4)

The head nurse and/or dialysis facility administrator most commonly determined whether the brochure would be disseminated to patients. Fifty-nine percent of head nurses and 25 percent of dialysis facility administrators determined whether the brochure would be distributed. Additionally, 17 percent of medical directors, along with nine percent of both dietitians and social workers, determined the brochure's dissemination.

Most facilities handed the brochure to patients and/or placed it somewhere accessible in their facility.

Seventy-four percent of facilities said they personally handed the brochure to patients, and 13 percent gave it to family members or a significant other. Although 47 percent of facilities reported placing the brochure somewhere accessible in the facility, only seven facilities relied exclusively on this method of dissemination. Brochures were most commonly placed in the patient waiting room or lobby area, and/or placed on the patient bulletin board. Twelve facilities used several of the above methods of distributing the brochure, three facilities let the staff decide how it would be distributed, and one facility translated it into Spanish first.

Thirteen percent of facilities did not distribute the brochure for a variety of reasons.

Of the thirteen percent of facilities (11 facilities) not distributing the brochure, two facilities didn't do so because they were either not calculating URR numbers at the time or were changing the measure of adequacy reported to patients. Another three facilities mentioned planning to distribute the brochure in the future. One facility reported not receiving enough copies of the brochure, one needed the Spanish version of the brochure, two facilities were still evaluating the brochure, and two facilities reported having their own "report card" or method of reporting URR or KT/V numbers to patients.

Half of the facilities reported distributing the brochure to every patient, while the other half said they distributed it to an average of 69 percent of patients.

Facilities were split evenly on whether they distributed the brochure to every patient or to only a portion of patients. Facilities not distributing the brochure to every patient, reported distributing it to an average of 69 percent of their patients. The modal distribution of the brochure was 78 percent of patients with a median distribution of 75 percent.

In two separate patient surveys reported in a companion OIG report (OEI-06-95-00320), only one-third of patients reported receiving the brochure. The discrepancy between the number of facilities receiving the brochure (76 percent) and the much lower number of patients saying they received the brochure could be explained, at least in part, by the fact that half of the facilities surveyed did not distribute the brochure to every patient.

For-profit facilities were almost three times as likely (74 vs. 26 percent) to distribute the brochure to every patient compared to non-profit or government-owned facilities (see table 3). There were significant differences in brochure distribution based on the type of facility administration. Hospital administered facilities were much less likely (18 vs. 82 percent) to distribute the brochure to every patient, compared to non-hospital administered facilities.⁸

Table 3: FACILITIES OWNERSHIP STATUS: PROFIT OR NON-PROFIT/GOVERNMENT by distribution of brochure			
	Distributed to every patient	Distributed to some patients	Brochure not distributed
Facility ownership			
Non-profit/Government	26 % (10)	48 % (14)	73 % (8)
For-profit	74 % (28)	52 % (15)	27 % (3)
Facility administration			
Hospital administered	18 % (7)	38 % (11)	45 % (5)
Non-hospital administered	82 % (31)	62 % (18)	55 % (6)

Among facilities not distributing the brochure to every patient, the most commonly reported reasons were: 1) their belief that many patients wouldn't understand the brochure's content (54 percent), and 2) they did not receive enough brochures to give one to every patient (37 percent). Time constraints prevented the distribution of the brochure to every patient according to five facilities, while four facilities said they didn't distribute it because they used other education materials instead. Other facilities not distributing brochures to each

patient reported the brochures were placed in the waiting area, they had already discussed the material with patients, or said disseminating the brochure was not a staff priority.

Eighty-four percent of facilities reported they personally explained the brochure to patients, with registered nurses providing the majority of these explanations.

Most facilities (84 percent) reported their staff personally explained the brochure to patients. Eighty percent of facilities said registered nurses provided these explanations. Thirty percent of dietitians, 18 percent of licensed vocational nurses (LVNs), and 17 percent of social workers in facilities also provided such explanations. Fifteen percent of doctors and 12 percent of technicians also provided explanations of the brochure to patients. Although several staff members might have provided these explanations, RNs had the greatest responsibility.

Facilities reported patients were usually alert but didn't always ask questions or didn't appear to understand staff explanations of the brochure. Almost all facilities (97 percent) said at least half or more of their patients appeared alert during their explanations. However, only 67 percent of facilities reported patients asked questions during these staff explanations, of which, 34 percent said only half of patients did so, and 33 percent said only a few.

In our patient surveys (OEI-06-95-00321), only 49 percent of patients from our first sample, and 42 percent from our second sample, remembered receiving an explanation of the brochure's content, although 84 percent of facilities reported giving explanations of the brochure to patients. This discrepancy suggests some patients may not have actively listened to the explanation, or the explanation may have been cursory or low key, and thus forgettable.

Seventy-three percent of facilities said a few patients didn't appear to understand the explanation, while another nine percent said most, or about half, of patients didn't understand.

The majority of patients, reportedly, were listening during staff explanations, with only 59 percent of facilities saying a few patients weren't listening. Seven facilities reported a few or more patients slept through the staff explanation. Additionally, 87 percent of facilities reported no patients objected to having the information explained to them, while only three facilities said that about half or more of their patients objected to such an explanation.

Facilities with at least 50 percent of their patients interested in finding out about how adequate their dialysis is were also significantly more likely to explain the brochure to patients. Ninety-two percent of facilities with over half of their patients interested in their adequacy information also explained the brochure, compared to 77 percent of facilities with fewer than half of their patients interested in adequacy information.

BROCHURE'S EFFECTIVENESS

Seventy-two percent of facilities rated the brochure's effectiveness as a patient educational tool as either excellent or good, and 66 percent said the brochure was somewhat, or very, easy for their patients to understand. Almost all facilities (98 percent) said patients need to know the information in the brochure, and 82 percent considered a brochure to be an appropriate method for communicating it to patients.

Facilities' ratings of brochure's effectiveness.

Twenty-one percent of facilities rated the brochure's overall effectiveness in educating patients as excellent, and another 51 percent rated it as good. Twenty-four percent of facilities felt the brochure did a fair job of achieving this goal, while only two facilities rated the effectiveness of the brochure in educating patients as poor or very poor.

Typical comments from facilities judging the brochure's effectiveness as excellent or good include the following: 1) "(It) was easy to understand with excellent and direct information;" 2) "Makes the patient and family aware of the need for adequate dialysis;" 3) "It was a good introduction to this topic and assisted staff in presenting information;" and 4) "Quick self-learning and backed up with concept we try to sell to patients."

A sampling of comments from facilities finding the brochure much less effective for educating patients listed several concerns: 1) "Doesn't address 24 week therapy, diabetes, residual function...;" 2) "The patients who most need information are the same ones who struggle to understand...;" 3) "Only some patients are interested;" 4) "Language is too sophisticated for most of our patients;" 5) "Mainly due to mismanaged distribution methods;" and 6) "Patients receive so much written material already, they don't pay attention..."

Facilities rating the brochure as excellent for educating patients were much more likely to report more of their patients were interested in adequate dialysis. For example, facilities rating the brochure as excellent reported 75 percent of their patients were interested in adequate dialysis. In contrast, facilities who did not give the brochure an excellent rating reported only 52 percent of their patients were interested in adequate dialysis (see table 4).

Facility rated brochure as excellent	Average percent of patients interested in adequate dialysis
Yes	75%
No	52%

Additionally, facilities rating the brochure as excellent in educating patients reported almost 1.5 times more of their patients track their URR or KT/V numbers from month to month (see table 5).

Table 5: PERCENT OF PATIENTS IN FACILITIES REPORTED TRACKING THEIR URR OR KT/V NUMBER MONTH TO MONTH by facilities rating the brochure as excellent	
Facility rated brochure as excellent	Average percent of patients tracking number
Yes	40%
No	27%

Facilities also were more likely to rate the brochure as excellent if their patients had been undergoing dialysis for a longer period of time (see table 6).

Table 6: AVERAGE MONTHS PATIENTS ON DIALYSIS PER FACILITY by facility rating of brochure	
Facility rated brochure as excellent	Average months patients on dialysis
Yes	55
No	41

Facilities' ratings of brochure's understandability.

Sixty-six percent of facilities thought the brochure was somewhat, or very, easy for most of their patients to understand.

The majority (66 percent) of facilities reported the brochure was either somewhat (38 percent), or very, easy (28 percent) for most patients to understand. Eighteen percent said it was neither easy nor hard to understand and, 14 percent said it was somewhat hard to understand. No facilities said the brochure was very hard to understand and only one facility reported not knowing how well patients understood the brochure's contents.

Our patient surveys (OEI-06-95-00320) showed an even higher number of patients (84 percent) thought the brochure was somewhat, or very, easy to understand. However, the inability of many patients to accurately recall key brochure concepts tempers their high ratings of ease of understanding the brochure somewhat.

Ten facilities reported most of their patients found the brochure's content somewhat hard to understand, citing several reasons for this difficulty in patient understanding. Six facilities found the use of the terms URR and KT/V too confusing, and five facilities said patients were unclear what number the brochure was talking about. Four facilities said the brochure's reading level was too high, and three facilities said the brochure's content was too advanced for their patients.

Facilities reporting the brochure as very easy to understand served patients with an average of 15 more months experience on dialysis (see table 7). Such a correlation suggests that patients undergoing dialysis for longer lengths of time may be more interested in or receptive to the brochure's content.

Table 7: AVERAGE MONTHS PATIENTS ON DIALYSIS PER FACILITY by facility rating of brochure	
Brochure rated as very easy to understand	Average months patients on dialysis
Yes	56
No	41

Forty-six percent of facilities reported most or all of their patients wanted to know their own URR or KT/V number after receiving the brochure, and 47 percent said half or more of their patients asked questions about the brochure's content.

Forty-six percent of facilities reported most or all of their patients wanted to know their own adequacy numbers after receiving the brochure. Forty-seven percent of facilities also reported about half or more of their patients asked questions about the brochure's content. However, 33 and 40 percent of facilities reported only a few patients wanted to know their own URR or KT/V numbers and/or asked questions after receiving the brochure, with six and three facilities, respectively, reporting none of their patients did either of these things.

Eighteen percent of facilities reported about half or more of their patients requested more information about their treatment, while 55 percent of facilities said only a few patients did this after receiving the brochure. Additionally, 22 percent of facilities said no patients made such an inquiry.

However, far fewer facilities reported any negative reaction to the brochure. Only 11 percent of facilities reported about half or more of their patients threw the brochure away without reading it, and 42 percent said only a few of their patients did this. Only ten percent of facilities reported about half or more patients were not interested in the brochure's information. Fifty-eight percent of facilities reported only a few patients were not interested in the brochure's information, and 13 percent of facilities said that none of their patients were not interested in the brochure's content.

Facilities' ratings of the importance of brochure's content.

Almost all facilities (98 percent) said patients need to know the information in the brochure.

Clearly, there is almost unanimous facility support of the adequacy information discussed in the brochure. Further, the two facilities disagreeing with the brochure's content said this was only because they had not seen a copy of the brochure or were already including this information on each patient's monthly lab report.

Almost all facilities had something positive to say about why the brochure's content provided critical information. The majority of these explanations stressed the importance of teaching patients to be actively involved in their dialysis, and noted the brochure could reinforce staff educational efforts and help patients better understand why they might have to increase their treatment time on the dialysis machines.

Specifically, the following comments represent the enthusiasm facility staff expressed about this information: 1) "More educated patients (are) more proactive and more responsible in their care...;" 2) "Encourage(s) compliance with attendance and patients to stay on prescribed times...;" 3) "Encourages patients to be more informed and take more responsibility," 4) "So patients will/can appreciate need for full time on dialysis;" 5) "The brochure helps reinforce information given by us;" 6) "The more (educational) information, the better;" and 7) "The more patients know about their illness, the better control they can have."

Facilities' ratings of using a brochure as educational tool.

Eighty-two percent of facilities reported a brochure is the method they would have used to communicate this information to patients, while 17 percent said they did not support the brochure as the method they would have used.

Facility staff supporting the brochure as the method they would have used to inform patients said this because the brochure is compact, to the point, easy to read and distribute, and gives patients and families a chance to review the information at a later time.

Others said the brochure was one of several methods they would have used, especially for their literate English-speaking population. A few staff also said they would supplement the brochure with a staff explanation of the information. Many staff members expressed the importance of visual aids and charts, such as the one in the brochure.

The following comments are typical of facility staff views on the usefulness of the brochure as an educational tool: 1) "They (patients) needed to see printed educational material to believe it's true;" 2) "Quick, self-learning and backed up concept trying to sell to patients;" 3) "Easy to reach all patients and we use them in our new patient orientation packets;" 4) "Was easy to understand - colors were good in attracting patient attention;" 5) "Best way to get information to patients;" 6) Important they look at and refer back to;" and 7) "Good teaching tool if individually given, otherwise not sure..."

Facility staff less supportive of using a brochure said they would have used a videotape instead, especially for less literate patients. Others would have used a computer-generated table of this information, or relied on individual verbal, face-to-face teaching, instead.

Facilities' use of the brochure in educational outreach materials.

Thirty percent of facilities reported they are already using the brochure or brochure's content in their educational outreach materials; others have plans to do so, and gave some plausible explanations why they have not.

Almost one-third of facilities used the brochure in their educational outreach materials, mostly by including the material in their patient newsletter or using it in an educational in-service training, or to educate new patients. Other facilities used the brochure in teaching families, posting it on the patient bulletin board, and in reviewing the material with patients when going over monthly lab report cards.

Although 70 percent of facilities did not report including the brochure's content in their educational material, 31 of 55 facilities specifically explained why they had not included the brochure or its content in their outreach efforts.

Specifically, twelve facilities indicated they have no newsletter or educational outreach materials. Seven facilities were planning to include the brochure in their future outreach but four facilities said they had no need to do so. They feel handing the brochure out to all patients was enough, or that they continuously explain this information monthly. Four facilities said they haven't had an opportunity due to time constraints. One facility displayed the brochure in their lobby area. One facility didn't include the brochure because the language was too sophisticated for most of their patients.

Facilities' innovative methods in educating patients.

Facilities use a variety of innovative methods to educate ESRD patients about their treatment. Such innovative methods include using videotapes during patients' dialysis treatments, bulletin boards, posters, or wall charts; along with educational classes, in-service training, newsletters, and monthly report cards.

Videotape was the most frequently mentioned (ten facilities) method used to educate patients about their treatment. Videos can be used during patients' treatments and assure all patients better understand the material, even those with reading difficulties. One facility was using videos produced by local physicians and featuring their own patients.

Four facilities reported an innovative use of bulletin boards, wall charts, and patient incentive programs to improve dialysis treatment. Other facilities conduct patient in-service training, educational classes, and/or use a theme of the month to focus staff and patients on a particular topic. Facilities also employ monthly newsletters, report cards, and one-on-one teaching to educate patients about their treatment.

Four facilities conduct educational meetings before new patients first begin their treatment to help them better understand their future dialysis treatment. Two facilities use current patients to teach their new patients.

Facilities' recommendations for future educational initiatives.

Facilities recommended that future brochures for ESRD patients should be simplified, use layman's terms, and include more pictures, diagrams, and bright colors. Additionally, facilities recommended providing a larger supply of brochures so facilities can distribute them to every patient.

The majority of recommendations made by facilities (13 facilities) for future brochures for ESRD patients involved the presentation of the brochure's content. Facilities recommended brochures not be too detailed, but instead include; catchy titles, more visual explanations, more graphs, and larger type for visually impaired patients. Additionally, facilities recommended creating a separate brochure for patients with lower reading levels. One facility wanted the "Know Your Number" brochure to leave blanks on the recommended level of URR or KT/V numbers so facilities could assign higher levels for their patients, while one facility wanted to see the brochure split into two brochures, one discussing URR and one discussing KT/V.

Seven facilities recommended printing the brochure in additional languages, with the majority requesting Spanish brochures. These facilities apparently were not aware HCFA has already produced a Spanish version of the "Know Your Number" brochure which it will distribute shortly to facilities.

Six facilities recommended improvements in the distribution of future brochures, mainly by assuring they receive a larger supply of brochures; one for each patient, plus extras to display in certain areas of the facility. One facility reported confusion about how the brochures were distributed to patients. This facility never received the brochure and was told by their network that the brochures were mailed individually to patients. One facility recommended all staff members be informed prior to distributing the brochure to patients.

Six facilities wanted to see additional brochures on various topics that help patients improve their compliance and overall treatment. Recommended topics included: fluid compliance, phosphate binders, and calcium intake.

The creation of educational program videos for both patients and staff was recommended by two facilities, while one facility wanted to see follow-up material to the "Know Your Number" brochure, including a more in-depth explanation and a larger graph.

Lastly, two facilities suggested continuing communication from dialysis facilities to assure new patients receive introductory information about dialysis and the role of networks.

DIALYSIS ADEQUACY

Facilities said at least 50 percent of their patients are interested in the adequacy of their dialysis, with 29 percent tracking their numbers month-to-month. However, only 77 percent of facilities calculate patients' numbers at least monthly, with 21 percent doing this only quarterly. Further, only 53 percent of facilities give patients their numbers all the time; many do so far less, 16 percent do this less than half the time.

An average of 57 percent of patients from all facilities were reported to be interested in finding out how adequate their dialysis is. The modal percent of interested patients was 50 percent, with a median of 60 percent of patients interested in knowing the adequacy of their dialysis.

The majority of facilities (77 percent) calculate patients' URR or KT/V numbers at least monthly, but 21 percent of facilities calculate such numbers only on a quarterly basis, and 3 facilities calculate adequacy numbers only as ordered by the doctor or other staff members.

Free-standing facilities were more likely to report more of their patients are interested in finding out about the adequacy of their dialysis and were also more likely to calculate patients' adequacy information on a monthly basis, compared to hospital-based facilities.

Free-standing facilities were more likely (61 vs. 42 percent) to report half or more of their patients were interested in finding out how adequate their dialysis is, compared to hospital-based facilities. Free-standing facilities were also three times more likely (76 vs. 24 percent) to calculate patients' adequacy numbers at least monthly compared to hospital-based facilities.

Facilities who calculate their patients' numbers monthly or more often were much more likely to have distributed the brochure to every patient.

Of facilities reporting they distributed the brochure to every patient, 87 percent said they also calculated patients' URR or KT/V numbers at least on a monthly basis. In contrast, of facilities distributing the brochure to just some of their patients or to none at all only 62 and 64 percent, respectively, calculated patients' URR or KT/V numbers at least monthly. (see table 8)

Table 8: FREQUENCY OF CALCULATING PATIENTS' URR OR KT/V NUMBER by distribution of brochure			
Number calculated	Distributed to every patient	Distributed to some patients	Brochure not distributed
Monthly or more	87% (33)	62% (18)	64% (7)
Less than monthly	13% (5)	38% (11)	36% (4)

Facilities with patients averaging 14 months longer on dialysis (48 months vs. 34 months) were significantly more likely to calculate and share patient URR or KT/V numbers on a monthly basis (see table 9).

Table 9: AVERAGE MONTHS PATIENTS ON DIALYSIS PER FACILITY by facilities giving monthly URR or KT/V numbers to patients	
Number calculated monthly	Total months patients on dialysis
Yes	48
No	34

Although 53 percent of facilities said they give patients their URR or KT/V numbers all the time, many facilities reported doing so far less, with 16 percent giving this information less than half of the time.

The majority (53 percent) of facilities report giving patients their URR or KT/V numbers 100 percent of the time, while 27 percent give this information only 75 percent of the time. Nine percent of facilities say they give this adequacy information to patients only half of the time, and seven percent of facilities only do so 25 percent of the time.

Four percent of facilities never give patients information about their URR or KT/V numbers. Two facilities gave the following reasons for not sharing this information: 1) "Most outpatients are very sick. We are a hospital-based unit," and 2) "Most patients are not interested or didn't understand URR or KT/V at the time the brochure came out."

In our patient surveys (OEI-06-95-00320), we found only 45 percent in our first sample and 35 percent in our second sample identified the URR test as one used in their dialysis facility to measure the adequacy of their dialysis, with even fewer identifying the KT/V test (37 and 36 percent). Additionally, about one-quarter of all patients sampled said they did not know which test(s) were used by their dialysis facility to measure adequacy.

Free-standing facilities were twice as likely (64 vs. 32 percent) to give patients their URR or KT/V numbers 100 percent of the time, compared to hospital-based facilities.

Of facilities distributing the brochure to every patient, 73 percent also say they give patients their URR or KT/V number 100 percent of the time, compared to 43 and 36 percent of facilities distributing it to a portion of their patients or not distributing the brochure at all. (see table 10)

Table 10: FREQUENCY PATIENTS GIVEN URR OR KT/V NUMBER by distribution of brochure			
Frequency number given	Distributed to every patient	Distributed to some patients	Brochure not distributed
100% of time	73% (27)	43% (12)	36% (4)
50-75% of time	19% (7)	46% (13)	27% (3)
25% of time to never given	8% (3)	11% (3)	36% (4)

Facilities reporting higher percentages of patients interested in adequate dialysis also were significantly more likely to give patients their URR or KT/V number 100 percent of the time, than facilities reporting patients with lower interest in adequate dialysis. Facilities giving adequacy information 100 percent of the time were over 1.5 times more likely (64 vs. 41 percent) to also report patients were interested in adequate dialysis (see table 11). Although we don't know whether patients are more interested in adequate dialysis because they are more frequently given this information or visa-versa, an observable correlation exists between these variables, suggesting the importance of both of these important elements.

Table 11: PERCENT OF PATIENTS IN FACILITIES REPORTED INTERESTED IN ADEQUATE DIALYSIS by frequency patients are given URR or KT/V number	
Frequency of patients given URR or KT/V #	Average percent of patients interested in adequate dialysis
100% of time	64% (55)
50-75% of time	54% (39)
25% of time to never given	41% (11)

Significant differences also existed in the frequency with which some facilities gave patients their URR or KT/V numbers based on the percentage of Hispanic patients and patients of other backgrounds, such as Indian, Lebanese, and/or Hawaiian/Samoan (see table 12). Facilities with a higher proportion of these patients were much more likely to not give their patients adequacy information on a regular basis. Additionally, near significant differences existed based on the percentage of black patients per facilities. Facilities distributing adequacy information only 25-50 percent of time also had a majority of black patients, instead of a majority of white patients.

Table 12: FREQUENCY PATIENTS GIVEN URR OR KT/V NUMBER by distribution of patients by race					
Frequency # given	Distribution of patients in facilities by race				
	% White	% Black	% Hispanic	% Asian	% Other
100% of time	47%	44%	5%	2%	2%
75% of time	47%	33%	14%	5%	1%
50% of time	38%	44%	1%	3%	14%
25% of time	30%	56%	5%	7%	2%
Never	54%	17%	26%	0%	3%

Facilities reported an average of 29 percent of their patients track their URR or KT/V numbers from month to month; patients given this information all the time are significantly more likely to track their numbers.

Vast differences existed in the percentage of patients tracking URR or KT/V information from month to month, as reported by facilities. Just under one-third of facilities reported ten percent or fewer of their patients track this information, with the median number of patients who track their number being 25 percent. Nevertheless, the largest number of facilities (19 percent) reported 50 percent of their patients track adequacy information.

Facilities reporting higher percentages of patients tracking URR or KT/V numbers on a monthly basis also were significantly more likely to also be facilities who report they give patients this information all the time (see table 13). Facilities giving this information 100 percent of the time averaged 35 percent of their patients tracking adequacy information, compared to only 25 and 14 percent of facilities giving this information 50-75 percent of the time or less.

This correlation reinforces the importance of facilities giving this information to their patients every time it is calculated, so that patients can actively participate in their dialysis care.

Table 13: Percent of patients in facilities reported tracking URR or KT/V number from month to month by frequency patients are given URR or KT/V number	
Frequency of patients given URR or KT/V #	Mean of patients tracking number
100% of time	35 % (49)
50-75% of time	25 % (35)
25% of time to never given	14 % (7)

Facilities regularly share patients' phosphorus, potassium, albumin, and B.U.N. test results with them.

In addition to facilities sharing information about patients' URR or KT/V test results, 98 and 97 percent of facilities reported they regularly share phosphorus and potassium test results with patients, while 95 and 93 percent share patients' albumin and B.U.N results. Thirty-five percent of facilities also share patients' HCT/Hematocrit test results, while 29 percent give patients their calcium test results regularly. The protein catabolic rate is shared with patients by 25 percent of facilities and iron test results are shared by 15 percent of facilities. Additional test results regularly shared with patients include: creatinine, glucose, cholesterol, ferritin, and Hgb/Hemoglobin. The only facility reporting they do not share test results with patients regularly also said only 10 percent of their patients were interested in adequate dialysis. This same facility said it calculates URR and/or KT/V numbers on a monthly basis but never shares these test results with patients.

Additionally, the results of our surveys (OEI-06-95-00320) showed patients most frequently identified the potassium test (60 and 61 percent of patients) and the phosphorus test (55 and 58 percent) as being used by their dialysis facility to measure adequacy, rather than the URR or KT/V test.

RECOMMENDATIONS

Overall, we found the brochure has the potential to serve as an effective part of a broader strategy of improving patients' understanding of adequate dialysis and enlisting their support in monitoring the adequacy of their dialysis. The "Know Your Number" brochure was given a positive assessment by facilities receiving it. However, the brochure was not received by all facilities, nor was it fully distributed or explained to all patients by all receiving facilities.

Facilities receiving the brochure were receptive to the brochure's content, reporting it was essential information for patients to understand. Nevertheless, facilities varied greatly in how they embraced the brochure's concepts in practice, with some fully engaging patients in understanding their own adequacy information by calculating their URR or KT/V number on a monthly basis and regularly giving these numbers to patients, while others provide key adequacy information to patients far less often. Yet, when facilities do provide this adequacy information, it appears to increase patient interest and involvement in monitoring the adequacy of their dialysis. It seems clear that the brochure's effectiveness in educating patients and involving them in monitoring dialysis adequacy is heavily dependent upon facility practices and the quality of staff-patient relationships.

Based on our findings, we recommend that HCFA take the following actions to improve kidney dialysis:

DISSEMINATION. Assure all facilities receive an ample supply of brochures and should encourage them to distribute a brochure to every patient. HCFA might also consider providing guidelines to facilities on effective dissemination approaches.

BROCHURE CONTENT & FORMAT. Simplify the language and concepts as much as possible in any subsequent or revised patient brochures. Consideration might be given to developing alternate versions of the brochure for different reading levels and to add greater use of color and graphics to gain interest and promote patient understanding.

CONTINUING PATIENT EDUCATION. Encourage continuing efforts by facilities to educate patients and to reinforce the importance of patient understanding and monitoring of the adequacy of their dialysis. A training video to introduce and/or reinforce the brochure concepts might also prove effective, based on the suggestions and experiences of some facilities.

USE OF ADEQUACY MEASURES. Encourage facilities to calculate dialysis adequacy measures on a monthly basis and share these numbers with patients on a regular basis in order for the brochure to achieve its intended impact on patients and facilities.

AGENCY COMMENTS

The Health Care Financing Administration (HCFA) concurred with all the report's recommendations. We appreciate their responsiveness to our proposals. However, we have a new concern that has arisen since we issued our draft report.

We originally recommended that HCFA encourage facilities to calculate dialysis adequacy monthly and share these numbers with patients on a regular basis. HCFA informed us that they had no requirement for facilities to measure the adequacy of dialysis at prescribed intervals but that their revised ESRD Conditions for Coverage will require facilities to calculate the adequacy of dialysis quarterly. This is in marked contrast to the upcoming National Kidney Foundation's Dialysis Outcome Quality Initiative guidelines which recommend a standard practice guideline of a monthly URR or KT/V calculation, not quarterly calculations. We are concerned that facilities will interpret HCFA's Conditions for Coverage as the acceptable standard and conduct adequacy testing only quarterly.

In our view, this could pose a severe health risk for ESRD patients whose dialysis could go three months before needed corrections could be made to their treatment. We are convinced that facilities should be required to calculate adequacy numbers monthly and we urge HCFA to reconsider or amend the Conditions for Coverage accordingly.

Discussion of Technical Comments

HCFA suggested we assess whether some of the comprehension issues might be attributed to a lack of cultural sensitivity in the brochure. We did analyses looking at both a patient's race and primary language. However, we found no statistically significant differences on key questions related to comprehension based on these two variables.

Additionally, HCFA called attention to the Spanish version of the brochure. We were happy to mention that 50,000 brochures would be printed for later distribution in the background section of both reports. Of course this study examined only the English version; at the time of our facility survey the Spanish version had not been distributed.

See Appendix C for a full text of HCFA's comments.

ENDNOTES

1. Title 42 CFR 405.2102, Conditions for Coverage of Suppliers of ESRD Services, October 1993; pg. 127.
2. Hemodialysis therapy cleans and filters a patient's blood with a dialyzer. This procedure can be done at home or in-center by nurses or trained technicians. Hemodialysis is usually performed about three times a week, with treatments lasting 2 to 4 hours each. Through this treatment and a proper diet, ESRD patients can greatly reduce the amount of wastes building up in their blood.
3. Peritoneal Dialysis replaces the work of the kidneys by removing extra water, wastes, and chemicals from the body. A cleansing solution, called dialysate, helps facilitate a patient's peritoneal membrane of the abdomen to filter their blood, requiring a catheter to be permanently placed into their abdomen. Wastes are filtered from a patient's body once the dialysate is drained. There are three types of peritoneal dialysis, with Continuous Ambulatory Peritoneal Dialysis (CAPD) being the most common.
4. The Urea Reduction Ratio (URR) informs patients how well hemodialysis is working by telling them the percentage of urea (waste products) removed from their body during their treatment.
5. Some dialysis facilities calculate a KT/V ratio instead of URR. This urea kinetic model or index is defined as the dialyzer urea clearance (K) multiplied by the patients' treatment time (T) divided by the volume of urea distribution (V).
6. Consensus Development Conference Panel. Morbidity and mortality of renal dialysis: An NIH consensus conference statement. *Ann Intern Med*, 1994; 121: 62-70.
7. Renal Physicians Association. Clinical practice guideline on adequacy of hemodialysis: Clinical practice guideline, number 1. December, 1993
8. Strong linkages exist between facilities' ownership type and the way they are administered. Over three-fourths (79 percent) of the non-profit/government-owned facilities are also administered by a hospital, while only one for-profit facility was administered by a hospital.

APPENDIX A

RESPONDENT FACILITY PROFILE

Key facility characteristics

Sixty-seven percent of our facilities were free-standing, while 30 percent were attached to a hospital, and three percent were part of a clinic or medical complex. Sixty-five percent of facilities were non-hospital administered and 35 percent were hospital administered. The majority (56 percent) of responding facilities were for-profit, 39 percent were not-for-profit, and five percent were government facilities.

Forty-three percent of dialysis facilities were located in urban areas, 29 percent in suburban areas, and 28 percent in rural areas. Our responding dialysis facilities had an average of 16 dialysis stations, ranging between two and eighty. The median number of dialysis stations was 13.

The average length of participation in Medicare/Medicaid for responding facilities was 11 years, with four facilities participating for only one year and eight facilities participating for 20 years. The mode for our facilities was 19 years (27 facilities) and the median was 11 years.

Patient education responsibilities

Sixty-four percent of responding facilities had a primary person in charge of patient education. Eighty-nine percent of facilities listed registered nurses as the position primarily responsible for patient education, while 66 and 59 percent of facilities, respectively, listed the dietitian and/or social worker as having this role. Doctors provided patient education in 43 percent of facilities, dialysis facility administrators in 21 percent, technicians in 34 percent, and LVNs in 26 percent of facilities. Other staff members playing a primary role in educating patients include the education or inservice coordinator and the director of nursing. Three facilities specifically mentioned that everyone in the facility or a specific staff team is in charge of patient education.

FACILITY PATIENT DEMOGRAPHICS

Average age of patients

The average estimated age of ESRD patients from responding facilities was 58 years old, with a range of patients between the ages of nine and 75. The mode and the median age estimated by our facilities was 60 years old, with 24 percent of facilities reporting 60 as their average patient age.

Months patients on dialysis

Facilities reported their patients spent an average of 45 months on dialysis, with one facility ranging from patients only spending an average of one month on dialysis compared to 126 months on dialysis in another facility. The mode number of months patients spent on dialysis was 24 months, with a median of 37 months.

Patients' disability level

Facilities estimated that an average of 22 percent of their patients have a disability that limits their ability to read or understand information. Two facilities reported none of their patients had limiting disabilities, while 59 facilities said less than 24 percent of their patients have a disability. Five facilities reported 75 percent or more of their patients had disabilities that limit their ability to read or understand information. However, 21 facilities reported between 25-49 percent of their patients had reading or comprehension disabilities and another 15 facilities said 50 percent or more of their patients had these disabilities.

Educational level

Seventy-eight percent of facilities reported information about their patients educational level. Facilities varied greatly in the educational level of their patients (see table 1). The highest percent of patients (43 percent) had high school diplomas. The average percent of patients with less than a high school education was 42 percent. Far fewer patients had some college (9 percent) or college/professional degrees (5 percent).

Table 1: PATIENT EDUCATIONAL LEVELS IN RESPONDING FACILITIES				
Patients' educational level	Average % of patients	Minimum %	Maximum %	Median %
Less than high school	42%	0% (3)	100% (1)	24%
High school diploma	43%	0% (3)	100% (2)	40% (6)
Some college	9%	0% (12)	60% (1)	5% (12)
College or professional degree	5%	0% (21)	40% (1)	4% (2)

Racial Composition of Patients

One hundred and five facilities reported the racial composition of their patients. White patients represented the largest racial group (45 percent). Black patients represented 40 percent of patients in responding facilities (see table 2).

Table 2: PATIENT RACIAL COMPOSITION IN RESPONDING FACILITIES				
Patients' racial composition	Average % of patients	Minimum %	Maximum %	Median %
White	45%	0% (10)	100% (4)	40% (11)
Black	40%	0% (11)	100% (2)	40% (6)
Hispanic	7%	0% (57)	100% (1)	0% (57)
Asian	3%	0% (72)	57% (1)	0% (72)
Other	3%	0% (83)	69% (1)	0% (83)

FACILITY STAFF RESPONDENT PROFILE

Sixty-seven percent of our facility surveys were completed by just a single respondent, while two staff members completed 16 percent of our surveys, and three surveys were completed by a team of three. Our surveys were most frequently completed by registered nurses (47 percent), while facility administrators completed 20 percent. Dietitians completed 15 percent of the surveys, with social workers and director of nursing or nurse managers completing 13 percent. Clinical coordinators completed six percent of our surveys.

Of the 25 facilities completing the survey in teams of two or three staff members, the most common combination of staff was registered nurses and the director of nursing, or the facility administrator and registered nurses.

APPENDIX B

ESTIMATES AND CONFIDENCE INTERVALS

The chart below summarizes the estimated proportions and the 95 confidence intervals for key statistics presented in this report based on this simple random sample.

Table 1: POINT ESTIMATES AND CONFIDENCE INTERVALS FOR KEY QUESTIONS.		
QUESTION	POINT ESTIMATE	95% CONFIDENCE INTERVAL
Proportion of facilities receiving the brochure.		
<u>Overall</u>	76%	68.1% - 83.9%
Urban	64%	50.3% - 77.7%
Suburban	81%	67.2% - 94.8%
Rural	93%	83.9% - 100%
Proportion of facilities handing brochure to patients.		
	74%	64.7% - 83.3%
Proportion of facilities distributing brochure to every patient.		
	50%	38.5% - 61.5%
For-profit facility ownership by distribution of brochure.		
	74%	60.1% - 87.9%
Hospital administered facility by distribution of brochure.		
	18%	5.8% - 30.2%
Proportion of facilities providing an explanation of brochure to patients.		
	84%	75.6% - 92.4%
Proportion of patients in facilities appearing alert during the staff explanation.		
	59%	46.3% - 71.7%
Proportion of facilities rating brochure as excellent or good.		
	72%	61.9% - 82.1%
Proportion of facilities rating the brochure as somewhat or very easy for patients to understand.		
	66%	55.0% - 77.0%

Table 1: CONT.		
QUESTION	POINT ESTIMATE	95% CONFIDENCE INTERVAL
Average percent of patients interested in finding out about adequate dialysis.		
	57%	51.4% - 62.6%
Proportion of facilities calculating patients' URR or KT/V number(s) at least monthly.		
	77%	59.9% - 84.8%
Proportion of facilities calculating URR or KT/V number(s) monthly by type of distribution of the brochure.		
<u>Type of distribution:</u>		
All patients	87%	76.3% - 97.7%
Some patients	62%	44.3% - 79.7%
No patients	64%	35.6% - 92.4%
Proportion of facilities giving adequacy information to patients 100 percent of the time.		
	53%	43.4% - 62.0%
Proportion of patients in facilities tracking their adequacy numbers monthly.		
	29%	24.4% - 34.4%
Proportion of facilities giving patients their potassium test results regularly.		
	97%	93.8% - 100%

TESTS FOR SIGNIFICANCE

Differences between the way facilities responded to the survey; whether they thought the brochure was excellent or not, whether they thought it was very easy to understand or not, and whether they calculated patients' URR or KT/V numbers at least on a monthly basis or not, were tested for significance for several questions. The table below shows the difference between groups and the resulting value when a t-test was performed.

Table 2: TESTS FOR SIGNIFICANCE FOR KEY QUESTIONS.			
QUESTION	RATED BROCHURE AS EXCELLENT		T VALUE
	YES	NO	
Average % of patients in facilities interested in adequate dialysis	75.1%	52.3%	2.89 ^{***}
Average % of patients in facilities tracking their URR or KT/V numbers monthly	40.1%	27.1%	1.42
Average months patients on dialysis per facility	55 months	41 months	2.05 ^{**}
QUESTION	RATED BROCHURE AS VERY EASY TO UNDERSTAND		T VALUE
	YES	NO	
Average months patients on dialysis per facility	55 months	41 months	1.90 [*]
QUESTION	URR OR KT/V # CALCULATED AT LEAST MONTHLY		T VALUE
	YES	NO	
Average months patients on dialysis per facility	48 months	34 months	3.13 ^{***}

* Indicates significance at the 90% confidence level.

** Indicates significance at the 95% confidence level.

*** Indicates significance at the 99% confidence level.

APPENDIX C

TEXT OF AGENCY COMMENTS



The Administrator
Washington, D.C. 20201

IG	_____
BAIG	_____
SAIG	_____
FDIG	_____
DIG-AS	_____
DIG-EC	_____ /
DIG-EI	_____ /
DIG-OI	_____
DIG-MP	_____
ARG-LC	_____
OGCIG	_____ /
ExecSec	_____
Date Sent	12-30

DATE: DEC 22 1996

TO: June Gibbs Brown
Inspector General

FROM: Bruce C. Vladeck
Administrator

SUBJECT: Office of Inspector General (OIG) Draft Reports: "Know Your Number"
Brochure -- Perspectives of Dialysis Patients (OEI-06-95-00320) and
"Know Your Number" Brochure - Experiences of Dialysis Facilities
(OEI-06-95-00321)

We reviewed the above-referenced reports which examine the effectiveness of the Health
Care Financing Administration's End Stage Renal Disease program.

Our detailed comments on the report recommendations are attached for your
consideration. Thank you for the opportunity to review and comment on these reports.

Attachment

Comments of the Health Care Financing Administration (HCFA) on
Office of Inspector General (OIG) Draft Reports:
"Know Your Number" Brochure - Perspectives of
Dialysis Patients, (OEI-06-95-00320) and "Know Your Number" Brochure -
Experiences of Dialysis Facilities, (OEI-06-95-00321)

"Know Your Number" Brochure - Perspectives of Dialysis Patients, (OEI-06-95-00320)

OIG Recommendation 1

HCFA should ensure future patient brochures are received by all Medicare dialysis patients.

HCFA Response

We concur. Direct mailing of brochures to patients was considered for our initial brochure distribution. However, the American Association of Kidney Patients recommended that the brochure be distributed through facilities where questions can be asked and explanations provided. If possible, future distributions will be a combination of direct mailing to patients and bulk mailing to facilities.

OIG Recommendation 2

HCFA should build on the patient/staff relationship in order to improve patient understanding of urea reduction ratios and the urea kinetic model and the importance of achieving adequate dialysis.

HCFA Response

We concur. The patient/staff relationship is critical to the improvement of a patient's understanding of end-stage renal disease (ESRD). Most patients rely on their care givers for necessary information and encouragement in order to be active participants in the health care decisions that involve them. Facility guidelines that provide the staff with additional background materials and suggestions on successful ways to use the brochure in patient education would support patient/staff dialogue as well as patient empowerment. However, it will not guarantee that the brochure will be distributed or that dialogue will occur.

"Know Your Number" Brochure - Experiences of Dialysis Facilities, (OEI-06-95-00321)

OIG Recommendation 1 (Dissemination)

HCFA should ensure that all facilities receive an ample supply of brochures and encourage them to distribute a brochure to every patient. HCFA might also consider providing guidelines to facilities on effective dissemination approaches.

HCFA Response

We concur. The initial distribution was intended to provide all ESRD dialysis facilities with enough brochures for 100-percent patient distribution plus extra brochures for anticipated new patients. The mailing labels and distribution amounts were provided long before the brochures were actually mailed. Consequently, some new facilities were not on the list. To the extent possible, future mailings will be done from the most current roster of facilities. Additional brochures will be sent to the Networks with a request that they send an ample supply to all facilities added to their Network rolls after the mailing list was created.

HCFA worked closely with the renal community (Renal Physicians' Association, American Association of Kidney Patients, National Kidney Foundation, American Nephrology Nurses Association, National Renal Administrators' Association, ESRD Network Forum and National Association of Nephrology Technicians) in the development and distribution of the brochure, as well as alerting the renal community to the brochure distribution. The national associations were most helpful in promoting the brochure at their national meetings and in their newsletters, as well as distributing brochures to their membership. The initial bulk mailing to facilities was accompanied by a letter of introduction that described the brochure development and encouraged facilities to use the brochures for patient education. We realize that continued and additional facility support are needed and that facilities which need the most support with the utilization of the brochure do not belong to or attend the various national meetings provided by the renal community. We will consider developing facility guidelines describing brochure distribution to patients and staff for patient education. The guidelines, if developed, will be included in future brochure bulk mailings to dialysis facilities.

OIG Recommendation 2 (Brochure Content and Format)

HCFA should simplify the language and concepts as much as possible in any subsequent or revised patient brochures. Consideration might be given to developing alternate versions of the brochure for different reading levels and to add greater use of color and graphics to gain interest and promote patient understanding.

HCFA Response

We concur. We appreciate the concern expressed regarding the language and concepts presented in the brochure. The National Renal Physicians' Association has a professional level brochure. There is also a high school level brochure on the topic. It is important for staff/patient dialogue to occur if a patient has difficulty understanding this brochure and needs the concepts explained further. Consideration can also be given to developing alternate versions of the brochure for different reading levels if needed and resources permit. Development of numerous versions of the brochure does not guarantee that all patients will get a copy, that the facility will educate their patients, or that all patients will be interested in learning about ESRD. Careful distribution plans would need to be developed to enable a variety of versions of the brochure to be effectively distributed so that the brochure supply and the need would coincide.

In considering reaching renal patients with information about adequacy of dialysis, the need for a Spanish version of the brochure became apparent. We have, therefore, had the brochure translated into Spanish and distributed to facilities with Spanish-speaking patients. Since all facilities were supposed to receive copies of the English version of the brochure with the introduction letter, we included information about the availability of the Spanish translation in the letter. As a result, we have had a number of requests for the Spanish version from facilities who were not on the original Spanish brochure distribution list.

We originally designed the brochure to have larger print and brighter, more varied colors. However, the Government Printing Office only allows a two-color process for printing brochures, and budgetary considerations reduced the size of the brochure. Future printings of the brochure will be more sensitive to the visually-impaired and more visually stimulating if at all possible.

OIG Recommendation 3 (Continuing Patient Education)

HCFA should encourage continuing efforts by facilities to educate patients and reinforce the importance of patient understanding and monitoring of the adequacy of their dialysis. A training video to introduce and/or reinforce the brochure concepts might also prove effective, based on the suggestions and experiences of some facilities.

HCFA Response

We concur. If funding permits, a training video to educate patients and reinforce the brochure concepts would probably be very helpful and well received. Having the brochure information on video would allow the visually-impaired to either better see the concepts or at least hear the concepts. Supporting patient/staff dialogue would still be needed.

In addition, since facility staff, in conjunction with the patient, are required to periodically review and update the patient's care plan, perhaps staff can be encouraged to take this opportunity to explain the information to patients and answer questions or address any concerns about the information in the brochure.

OIG Recommendation 4 (Use of Adequacy Measures)

HCFA should encourage facilities to calculate dialysis adequacy measures on a monthly basis and share these numbers with patients on a regular basis in order for the brochure to achieve its intended impact on patients and facilities.

HCFA Response

We concur. At this time there is no requirement for facilities to measure the adequacy of dialysis at prescribed intervals. Although the revised ESRD Conditions for Coverage, scheduled for release in early 1997, will require dialysis facilities to calculate the adequacy of dialysis quarterly, we encourage more frequent calculations as part of the facilities continuous quality improvement program.

The Facilities of Achievement Initiative will demonstrate, in volunteer ESRD dialysis facilities with existing computer capacity, the possibility of collecting medical indicators on 100 percent patient sample, then collating and analyzing the data and returning it to the participating facility for use in developing quality improvement interventions. The clinical indicators of the care received will be submitted to HCFA on a quarterly basis.

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Technical Comments

The report should assess whether some of comprehension issues of the beneficiaries might be attributed to a lack of cultural sensitivity in the presentation. Not only is there the relatively large number of Hispanics in the ESRD program, but also American Indians and African-Americans are represented in the population disproportionately.

We also note that the report failed to mention that there was a Spanish edition of this publication. This is particularly important considering the large Hispanic community affected by ESRD.