
Quality of Life and Patient Satisfaction: ESRD Managed Care Demonstration

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To study the effects of managed care on dialysis patients, we compared the quality of life and patient satisfaction of patients in a managed care demonstration with three comparison samples: fee-for-service (FFS) patients, managed care patients outside the demonstration, and patients in a separate national study. Managed care patients were less satisfied than FFS patients about access to health care providers, but more satisfied with the financial benefits (copayment coverage, prescription drugs, and nutritional supplements) provided under the demonstration managed care plan (MCP). After 1 year in the demonstration, patients exhibited statistically and clinically significant increases in quality of life scores.

INTRODUCTION

It has been postulated that an MCP can provide better and more comprehensive health care at a lower cost (Starr, 2000). However, it has also been stated that the main disadvantage of MCPs is the restrictive nature of their health care management approaches (Reschovsky, Kemper, and Tu, 2001). For instance, patients are

confined to a specific group of health care providers. This has often caused great dissatisfaction among patients who desire or need greater flexibility in their health care plan. Improving and maintaining patient satisfaction and quality of life have become important treatment goals in end stage renal disease (ESRD) (Kutner, Brogan and Kutner, 1986). Patient quality of life, as measured by the SF-36® (Medical Outcomes Trust, Inc., 2003), has been shown to predict morbidity, hospitalization, and mortality in dialysis patients (Hays et al., 1994). This investigation evaluates patient satisfaction and quality of life in the ESRD managed care demonstration.

The demonstration was conducted from 1996 to 2001 at three different sites: Health Options, Inc. (HOI), a subsidiary of Blue Cross®/Blue Shield® of Florida; Kaiser Permanente Southern California Region (Kaiser); and Xantus Health Care Corporation in Tennessee. Only the Florida and California sites remained operational for the duration of the demonstration. Enrollment was strictly voluntary. Recruitment materials were mailed by CMS to adult, Medicare primary, ESRD patients residing in the demonstration service area counties. The demonstration sites were also given opportunities to directly recruit ESRD patients and staff at local dialysis facilities. Patients were allowed to disenroll at any time.

The two active demonstration sites were based on different models of care. Kaiser was a large closed-system plan for specialists

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and inpatient care. In contrast to Kaiser's group-model structure, HOI relied on contracts with an independent network of providers to provide patient care. Both plans were based on a multidisciplinary team approach to patient-centered care management. Each enrollee was assigned to a team including a nephrologist, a case manager, a renal social worker, a dietitian, and a pharmacist; other relevant providers and specialists were included as needed. In most cases, the nephrologist also served as the patient's primary care provider in the MCP. Case managers were expected to be in daily contact with the nephrologist and coordinate the multidisciplinary team. Responsibilities of the case managers included monitoring patient care and promoting quality improvement, coordinating and managing patient needs, providing early intervention, and educating patients. The Kaiser case management team also included transplant coordinators, who provided case management for all transplant patients and worked to obtain transplants for qualified patients as quickly as possible. The coordinator also provided patient education and long-term post-transplant followup. Additional benefits provided by both plans included coverage for prescription drugs, other copayments, and nutritional supplements. Oppenheimer et al. (2003) fully describes marketing, enrollment practices, and benefit offerings in the demonstration.

Patient satisfaction was assessed from questions designed to measure satisfaction with services provided by dialysis facility and staff, and primary care physician. The questions also examined patient satisfaction with the benefits provided by the demonstration plans and the reasons why patients chose to enroll or not enroll. Patient quality of life was assessed using the SF-36® instrument, which has been validated to capture physical and mental

health scores for the ESRD patient population. Both patient satisfaction and quality of life data were collected on a questionnaire that was administered to demonstration patients and comparison groups.

METHODS

Sampling and Data Collection

Baseline data were collected on 1,479 demonstration patients, and followup data were collected on 750 one year after enrollment. The smaller sample size at followup was due to data collection and budgetary limitations, not patient attrition or disenrollment. This smaller sample was randomly selected from the larger baseline sample and a power analysis determined that this was the smallest sample size needed to detect a 5-point difference in quality of life scores.

For the evaluation of patient satisfaction, data on two different comparison groups were collected in a similar fashion and from the same dialysis facilities as the demonstration. The first comparison group consisted of 190 FFS patients and the second group was a sample of 190 managed care patients not enrolled in the demonstration—non-demonstration managed care (NDMC). Both of these samples were matched to the demonstration patients on age, race, and time since onset of ESRD.

In addition to the comparison groups, the quality of life analysis also compared demonstration patients to those from the Dialysis Outcomes and Practice Patterns Study (DOPPS), a nationally representative sample of hemodialysis patients in the U.S. (Young et al., 2000). The sample of DOPPS patients was restricted to California and Florida ($n=377$ and $n=539$, respectively).

As part of the evaluation data collection, experienced local nephrology personnel who were not part of the patient's dialysis

or transplant unit staff abstracted baseline medical record data and conducted in-person patient interviews on quality of life. A patient questionnaire (SF-36®) was used to assess patient satisfaction and quality of life and other targeted questions. The questionnaire was administered to demonstration patients in person by trained data collectors, usually while they were at the dialysis facility. For the DOPPS comparison sample, quality of life data were taken from patient questionnaires collected for all DOPPS patients. These forms were similar to the demonstration questionnaire and included the SF-36®, but were generally self-administered. The differences in the method of survey administration (self versus interviewer) may affect the completion rates and responses, but this was not adjusted for in the analyses.

Outcome Measures

Patient satisfaction measures from the questionnaire were grouped into three major categories: (1) reasons for joining the demonstration health plan, including cost of outpatient drugs, cost of copayments, and recommendation of doctor; (2) satisfaction with health care providers and services, including dialysis staff, medical team (e.g., primary physician, social worker, dietitian, and transplant medical team), dialysis facilities, and hospitals; and (3) satisfaction with health plan benefits, including copayment/cost requirements, medication costs, and access to nutritional supplements.

Patient quality of life was assessed using the SF-36®—a comprehensive short-form with only 36 questions—which yields an 8-scale health profile as well as summary measures of health-related quality of life. As is widely documented, the SF-36® has proven useful in monitoring general and specific populations, comparing the bur-

den of different diseases, differentiating the health benefits produced by different treatments, and in screening individual patients. The two measures of the SF-36® are the physical and mental component summary scores. Each of these comprises four related subscales: physical functioning, role—physical, bodily pain, and general health (physical component summary score); and vitality, social functioning, role—emotional and mental health (mental component summary score). This article presents results for each subscale as well as the two summary measures.

Statistical Analysis

All analyses were restricted to hemodialysis patients in the demonstration and all comparison groups. Chi-square statistics were used to test differences in proportions of satisfaction responses between the demonstration group at baseline versus 1 year followup and the demonstration group at followup versus the FFS and NDMC groups. The demonstration followup group was used in comparisons with the FFS and NDMC groups because the demonstration patients would have less experience (and a less accurate perception of satisfaction) with the demonstration at baseline rather than after 1 year. *T* statistics were used to test differences in mean quality of life scores from baseline to 1-year followup within the demonstration and the DOPPS samples. Statistical significance was interpreted at the 0.05 level for a two-tailed test.

Multiple linear regression analysis was used to detect differences in the adjusted quality of life scores between the managed care demonstration and the DOPPS sample. These quality of life models were adjusted for patient age, sex, race, and history of the following conditions: coronary artery disease, congestive heart failure, cerebrovascular disease, peripheral vascular

Table 1
Descriptive Statistics for End Stage Renal Disease (ESRD) Managed Care Demonstration and Comparison Groups: 1996-2001

Measure	Demonstration Groups		Comparison Groups			
	Kaiser	HOI	California DOPPS ¹	Florida DOPPS ¹	Non-Demonstration Managed Care	Fee-for-Service
Sample Size (<i>n</i>)	523	386	377	539	188	177
Age (Years)	57.6	60.3	60.3	61.8	61.4	59.1
Male (Percent)	62.2	61.8	54.4	57.7	54.6	54.2
Black (Percent)	26.1	47.3	16.1	35.4	31.5	36.5
Time on ESRD (Years)	3.2	3.7	2.3	2.0	4.1	5.5
Average Number of Comorbidities	3.8	3.3	3.7	4.2	3.3	3.3
Household Income				Percent		
< \$10,000	27.3	43.2	32.6	36.9	23.4	51.2
\$10,001 - \$40,000	61.7	48.4	48.4	49.8	64.8	39.2
> \$40,000	11.0	8.4	19.0	13.3	11.8	9.5
Medicare Insurance	—	—	63.4	71.7	66.5	80.1
Unable to Walk	18.7	15.4	34.0	30.6	28.6	22.0

¹ Among patients completing a patient questionnaire (response rate equals 60 percent).

NOTE: DOPPS is Dialysis Outcomes and Practice Patterns Study.

SOURCES: Pifer, T.B., Bragg-Gresham, J.L., Dykstra, D.M., and Held, P.J., University Renal Research and Education Association, Shapiro, J. R., Centers for Medicare & Medicaid Services, Oppenheimer, C.C., and Gaylin, D.S., National Opinion Research Center, Beronja, N., The Lewin Group, and Rubin, R.J., Georgetown University School of Medicine, 2003.

disease, hypertension, diabetes, chronic obstructive pulmonary disease, cancer, smoking, alcohol abuse, drug abuse, and HIV. These models were also adjusted for patient mobility status, nursing home status, albumin, time since onset of ESRD, body mass index, and visual determination of undernourishment. All statistical estimation was performed using SAS[®] version 8.0 (SAS[®] Institute Inc., 1997).

RESULTS

The response rates for the patient questionnaire were 85 percent for the demonstration patients at baseline, 84 percent for the demonstration patients after 1 year in the demonstration, and 98 percent for the FFS and NDMC comparison groups. The higher response rate in the comparison groups was largely due to a more clustered sampling and timely data collection efforts. The matched comparison groups were randomly selected from mostly the same dialysis facilities as demonstration patients, but the demonstration patients were

enrolled in a staggered manner over a wider geographic region. Therefore, data collection was more cumbersome and difficult for the demonstration patients than the clustered comparison groups, resulting in a slightly lower response rate.

For the DOPPS comparison sample, the response rate was approximately 60 percent. There was concern raised about the lower response rate in the DOPPS since healthier patients were more likely to complete the questionnaire, possibly introducing a bias toward healthier respondents for the DOPPS. However, a study of non-response showed no statistical difference between patient characteristics or quality of life scores between the respondents and non-respondents (Pifer et al., 2000).

The demonstration patients were generally healthier, younger, and had lower income than the comparison samples (Table 1). The characteristics of disenrollees (excluding death) were captured for 31 of 53 disenrollees at Kaiser, and for 53 of 119 disenrollees at HOI. The patients' ages, number of comorbidities, and days in

Table 2
Reasons for Enrolling or Staying in End Stage Renal Disease Managed Care Demonstration Health Plan, Percent Demonstration Patients at Baseline and Followup: 1998-2000

Reason	Health Options, Inc.		Kaiser Permanente	
	Baseline	Followup	Baseline	Followup
	Percent			
Cost of Outpatient Drugs	26.4	30.4	29.4	32.6
Cost of Copayments	21.0	20.3	31.2	29.1
Recommendation of Doctor	23.7	25.3	7.0	5.8
Other	10.4	11.6	12.6	13.4

NOTE: Other includes the following reasons listed on the Patient Questionnaire: Recommendation of a friend or relative, Choice of hospitals, Choice of doctors, Benefit for transportation to the dialysis unit, Out-of-area dialysis benefit for when you have to travel, Benefit for family supportive services, Benefit for home health care services, Location of dialysis facility, Support services provided by case managers or care managers, and Other.

SOURCES: Pifer, T.B., Bragg-Gresham, J.L., Dykstra, D.M., and Held, P.J., University Renal Research and Education Association, Shapiro, J.R., Centers for Medicare & Medicaid Services, Oppenheimer, C.C., and Gaylin, D.S., National Opinion Research Center, Beronja, N., The Lewin Group, and Rubin, R.J., Georgetown University School of Medicine, 2003.

the hospital prior to enrolling in the demonstration were similar between continuous enrollees and disenrollees at both sites (data not shown). These results indicate that patients who chose to enroll in the demonstration were healthier and younger, but after enrollment, there were no significant differences between the patients who disenrolled or stayed in the demonstration health plan.

SATISFACTION

Enrolling or Staying in the Demonstration

Among Kaiser patients, the two most commonly given reasons for enrolling in the demonstration MCP or staying in the new plan after a year were the coverage of outpatient drugs and copayments (Table 2). However, among HOI patients, the two main reasons were coverage of outpatient drugs and recommendation of their doctor. Coverage of copayments was still a major reason, but seemed to be less of a factor than the recommendation of their doctor. It is important to note that doctors did not receive additional financial benefit for enrolling patients in the demonstration, thereby reducing the likelihood of any selection bias. The major other reason

reported by both HOI and Kaiser patients for enrolling in the demonstration was lack of other health care coverage.

Satisfaction with Providers and Services

The demonstration patients reported a high level of satisfaction with their dialysis staff in terms of friendliness and interest, staff encouragement, and support. For both HOI and Kaiser patients, there were no significant differences between patient satisfaction with dialysis staff at baseline and after 1 year in the demonstration group.

Although the demonstration and comparison patients all reported a high overall satisfaction with their dialysis staff, Table 3 shows that a higher percentage of FFS patients (80.6 percent) versus demonstration patients at followup (71.3 percent) reported that their dialysis staff encouraged them to be independent ($p < 0.05$). Furthermore, a higher percentage of FFS and NDMC patients (89.0 percent, $p < 0.05$ and 88.2 percent, $p < 0.05$, respectively) were satisfied compared with the demonstration patients (81.6 percent) in terms of staff support in coping with kidney disease.

While the differences between the demonstration and comparison groups were significant for these two questions, it

Table 3
End Stage Renal Disease Managed Care Demonstration Patient Satisfaction with Dialysis Staff
Followup Versus Comparison Groups: 1998-2000

Measure	Demonstration (Followup)	Matched Fee-for-Service	Matched Non-Demonstration Managed Care
		Percent	
Question 1:14			
Friendliness and Interest of Dialysis Staff			
Excellent	36.9	33.1	*25.7
Good	60.9	65.7	*73.3
Poor	2.2	1.1	1.0
Question 1:15a			
Staff Encourages Me to Be Independent			
True	71.3	*80.6	72.2
False	13.6	11.4	10.2
Don't Know	15.1	*8.0	17.6
Question 1:15b			
Staff Supports Me in Coping with My Kidney Disease			
True	81.6	*89.0	*88.2
False	8.6	8.7	7.5
Don't Know	9.8	*2.3	*4.3

* $p < 0.05$.

SOURCES: Pifer, T.B., Bragg-Gresham, J.L., Dykstra, D.M., and Held, P.J., University Renal Research and Education Association, Shapiro, J.R., Centers for Medicare & Medicaid Services, Oppenheimer, C.C., and Gaylin, D.S., National Opinion Research Center, Beronja, N., The Lewin Group, and Rubin, R.J., Georgetown University School of Medicine, 2003.

should be noted that there were also significant differences in terms of patients who reported, “don’t know.” In other words, more comparison patients may have reported satisfaction with staff encouragement and support, but that does not mean that more demonstration patients reported dissatisfaction with these aspects of their health care; rather, more demonstration patients reported that they did not have an opinion about these questions.

Overall, demonstration patients at baseline and followup, as well as comparison patients, reported high satisfaction with care and services provided by their medical care team and dialysis facility. There were few significant differences in the demonstration group from baseline to followup.

However, Table 4 shows that FFS patients reported higher satisfaction compared with the demonstration patients in terms of ease in obtaining appointments with a primary doctor, ease in obtaining referral to a specialist, and availability of social workers and dietitians. FFS patients also reported significantly higher satisfaction with their

ability to get to and from their dialysis facility, but lower satisfaction with medical care when hospitalized.

There were few differences between the demonstration and NDMC groups, with the exception of satisfaction with waiting time to see a doctor for a scheduled appointment. NDMC patients reported less satisfaction with this measure (74.9 percent) versus demonstration patients (84.3 percent, $p < 0.01$).

Satisfaction with Health Plan Benefits

There were significant differences between the demonstration patients at baseline and followup and between the demonstration and comparison groups in terms of three major benefits provided by the demonstration plan: no copayments, free medications, and free nutritional supplements (Table 5). Within the demonstration group, significantly fewer HOI and Kaiser patients reported financial burdens at a year followup ($p < 0.0001$) compared with baseline. At the 1 year followup, HOI patients

Table 4
End Stage Renal Disease Managed Care Demonstration: Patient Satisfaction with Medical Team, Dialysis Facility, and Hospitals Versus Comparison Groups: 1998-2000

Measure	Demonstration (Followup)	Matched Fee-for-Service	Matched Non-Demonstration Managed Care
Percent Agreeing			
Patient Satisfaction with Medical Team			
Medical Care Provided by Primary Doctor is Excellent Satisfied with the Effort of My Health Care Team in Determining Whether I Could Have a Transplant	86.8	91.0	81.3
Overall Care from My Transplant Medical Team is Excellent Quality	75.8	82.0	82.6
Easy to Obtain Appointments with Primary Doctor	78.3	71.6	68.1
Easy to Obtain Referral to a Specialist	83.2	**92.8	80.6
Do Not Have to Wait Long to See My Doctor for a Scheduled Appointment	88.0	*93.9	84.8
Social Worker is Usually Available to See Me When Needed	84.3	80.2	**74.9
Dietitian is Usually Available to See Me When Needed	89.4	*94.8	88.8
	90.8	*96.0	92.6
Patient Satisfaction with Dialysis Facility			
Easy to Get to and from Dialysis at this Facility	90.9	*96.6	89.6
Care I Receive During Dialysis Is Excellent	91.0	90.4	90.1
Usually Able to Obtain Dialysis Schedule I Desire	91.3	94.3	94.5
Facility Provides Comfortable Atmosphere and Useful Amenities	92.8	92.5	94.1
Patient Satisfaction with Hospitals			
Medical Care When Hospitalized Is High Quality	85.3	*77.7	81.7
Hospital Choices are Satisfactory	86.0	80.7	84.5

* $p < 0.05$.

** $p < 0.01$.

SOURCES: Pifer, T.B., Bragg-Gresham, J.L., Dykstra, D.M., and Held, P.J., University Renal Research and Education Association, Shapiro, J.R., Centers for Medicare & Medicaid Services, Oppenheimer, C.C., and Gaylin, D.S., National Opinion Research Center, Beronja, N., The Lewin Group, and Rubin, R.J., Georgetown University School of Medicine, 2003.

also reported greater ease ($p < 0.01$) in obtaining nutritional supplements under the demonstration health plan, in contrast to the Kaiser patients, who reported no difference.

A significantly smaller percentage of demonstration patients reported financial burdens for copayments and medications as compared with the FFS and NDMC patients ($p < 0.0001$), while a significantly larger percentage of demonstration patients reported ease in obtaining nutritional supplements ($p < 0.0001$).

QUALITY OF LIFE

DOPPS Comparison to Demonstration

Managed care demonstration patients comprise a healthier group than most dialysis patients. Compared with a nationally rep-

resentative sample (DOPPS), demonstration patients have fewer comorbidities, better mobility, and higher albumin, on average. This better health is also reflected in their baseline quality of life. Crude baseline physical and mental component summary scores show the two demonstration sites having significantly higher scores than the State-specific DOPPS comparisons (Table 6).

After taking into account the variation due to differences in health factors between the demonstration and DOPPS, the statistically significant differences at baseline disappeared. Table 6 also shows the baseline scores after adjustments were made.

Matched FFS and NDMC Comparisons

The demonstration patients reported similar quality of life to the matched NDMC and FFS patients. Table 7 shows the samples

Table 5

**End Stage Renal Disease Managed Care Demonstration Patient Satisfaction with Health Plan Benefits Versus Comparison Groups:
1998-2000**

Measure of Satisfaction	Health Options, Inc.		Kaiser Permanente		Demonstration (Followup)	Matched		Matched Non-Demonstration Managed Care
	Baseline	Followup	Baseline	Followup		Fee-for-Service	Managed Care	
	Percent Agreeing							
Copayment/Patient Costs for My Medical Care is Especially Burdensome	31.0	**14.4	27.6	**6.7	9.6	**52.7	**34.5	
Cost to My Family for Medications is a Large Burden	20.5	14.9	26.8	**6.8	9.9	**52.4	**35.6	
Ability to Obtain Nutritional Supplements Easy and Beneficial Under this Health Plan	69.0	*84.4	81.2	88.1	87.2	**67.7	**67.8	

* $p < 0.01$.** $p < 0.0001$.

SOURCES: Pifer, T.B., Bragg-Gresham, J.L., Dykstra, D.M., and Held, P.J., University Renal Research and Education Association, Shapiro, J.R., Centers for Medicare & Medicaid Services, Oppenheimer, C.C., and Gaylin, D.S., National Opinion Research Center, Beronja, N., The Lewin Group, and Rubin, R.J., Georgetown University School of Medicine, 2003.

Table 6

End Stage Renal Disease Managed Care Demonstration Baseline Quality of Life Summary Scores Versus DOPPS Comparison Groups: 1996-2001

Group	Sample Size (n)	Physical Component Summary		Mental Component Summary	
		Crude	Adjusted	Crude	Adjusted
Kaiser Demonstration	523	*34.9	33.3	*47.4	46.7
California DOPPS	377	32.7	32.5	45.6	45.5
HOI Demonstration	386	*35.3	33.4	*48.9	47.4
Florida DOPPS	539	32.9	32.4	46.6	46.2

* $p < 0.05$.

NOTES: DOPPS is Dialysis Outcomes and Practice Patterns Study. Kaiser is Kaiser Permanente. HOI is Health Options, Inc.

SOURCES: Pifer, T.B., Bragg-Gresham, J.L., Dykstra, D.M., and Held, P.J., University Renal Research and Education Association, Shapiro, J.R., Centers for Medicare & Medicaid Services, Oppenheimer, C.C., and Gaylin, D.S., National Opinion Research Center, Beronja, N., The Lewin Group, and Rubin, R.J., Georgetown University School of Medicine, 2003.

Table 7

End Stage Renal Disease Managed Care Demonstration Baseline Quality of Life Scores Versus Non-Demonstration Managed Care and Fee-for-Service: 1998-2000

Group	Sample Size	Physical Component Summary	Mental Component Summary
Demonstration ¹	1,068	35.1	48.1
Matched Non-Demonstration Managed Care	188	*37.0	48.1
Matched Fee-for-Service	177	35.9	47.8

* $p < 0.05$.

¹ Includes all patients at baseline.

SOURCES: Pifer, T.B., Bragg-Gresham, J.L., Dykstra, D.M., and Held, P.J., University Renal Research and Education Association, Shapiro, J.R., Centers for Medicare & Medicaid Services, Oppenheimer, C.C., and Gaylin, D.S., National Opinion Research Center, Beronja, N., The Lewin Group, and Rubin, R.J., Georgetown University School of Medicine, 2003.

had generally similar unadjusted physical and mental component summary scores at baseline. No differences were seen in the mental component summary score for either comparison group, but the NDMC sample showed higher physical component summary scores.

Pre-Managed Versus Managed Care

One year following their enrollment in the demonstration, patients were asked to report their quality of life a second time. Table 8 shows that quality of life scores either stayed the same or increased for demonstration patients after 1 year of enrollment in the demonstration. Several of the physical and mental subscales showed statistically significant, and clinically meaningful increases as determined by a criterion of a ≥ 3 -point difference (Samsa et al., 1999; Hays and Woolley, 2000). In addition, the mental component

summary score showed a significant increase ($D=1.9$, $p < 0.001$) at the 1 year followup. Although results are shown for both sites combined, the effect of improved mental scores was seen in both demonstration populations independently.

In contrast to the demonstration quality of life scores increasing, Table 9 illustrates that 1 year change in quality of life for the nationally representative DOPPS sample showed some small, but statistically significant, decreases.

DISCUSSION

Patient Satisfaction

Health Plan Benefits

We found significant differences in patient satisfaction with the financial incentives provided by the demonstration plan. After 1 year of coverage, significantly fewer

Table 8
Quality of Life for End Stage Renal Disease Managed Care Demonstration Patients at Baseline and 1 Year Followup: 1998-2000

Measure	Baseline Mean ¹	1 Year Followup Mean	Change in Quality of Life	p-value from paired t-test
Physical Functioning	49.9	49.4	-0.5	0.7059
Role—Physical	39.7	43.0	3.3	0.1283
Bodily Pain	66.3	69.5	3.2	0.0390
General Health	48.3	48.3	0.0	0.9954
Physical Component Summary	36.6	36.4	-0.2	0.6126
Mental Health	71.2	74.7	3.5	0.0004
Role—Emotional	60.0	68.2	8.2	0.0004
Social Functioning	67.2	67.8	0.6	0.6592
Vitality	46.5	47.4	0.9	0.3912
Mental Component Summary	48.3	50.2	1.9	0.0006

¹ Restricted to patients with 1 year of followup; n=422.

SOURCES: Pifer, T.B., Bragg-Gresham, J.L., Dykstra, D.M., and Held, P.J., University Renal Research and Education Association, Shapiro, J.R., Centers for Medicare & Medicaid Services, Oppenheimer, C.C., and Gaylin, D.S., National Opinion Research Center, Beronja, N., The Lewin Group, and Rubin, R.J., Georgetown University School of Medicine, 2003.

Table 9
End Stage Renal Disease Managed Care Demonstration Quality of Life for DOPPS Comparison Group at Baseline and 1 Year Followup: 1996-2001

Measure	Baseline Mean ¹	1 Year Followup Mean	Change in Quality of Life	p-value from paired t-test
Physical Functioning	42.8	41.0	-1.8	0.0039
Role—Physical	33.3	32.4	-0.9	0.3894
Bodily Pain	60.5	58.9	-1.6	0.0191
General Health	41.9	41.0	-0.9	0.0503
Physical Component Summary	33.5	32.9	-0.6	0.0144
Mental Health	69.8	69.2	-0.6	0.2037
Role—Emotional	55.9	54.7	-1.2	0.3183
Social Functioning	64.9	62.9	-2.0	0.0041
Vitality	44.9	43.5	-1.4	0.0059
Mental Component Summary	48.1	47.7	-0.4	0.1215

NOTE: DOPPS is Dialysis Outcomes and Practice Patterns Study.

SOURCES: Pifer, T.B., Bragg-Gresham, J.L., Dykstra, D.M., and Held, P.J., University Renal Research and Education Association, Shapiro, J.R., Centers for Medicare & Medicaid Services, Oppenheimer, C.C., and Gaylin, D.S., National Opinion Research Center, Beronja, N., The Lewin Group, and Rubin, R.J., Georgetown University School of Medicine, 2003.

demonstration patients reported financial burdens due to the benefit of free medications and no copayments provided under the demonstration MCP. These financial incentives were also the most important reasons listed by the demonstration patients for enrolling and/or staying in the plan. It is not surprising that these are major incentives for ESRD patients given the high costs that they may incur for medications and copayments if they do not have supplemental insurance. Furthermore, demonstration patients tended to have lower incomes than the comparison

groups; therefore, these financial benefits would certainly be important incentives for enrolling and staying in the demonstration.

Surprisingly, neither the HOI nor Kaiser patients reported higher satisfaction with preventive care and wellness under the demonstration plan. This is one of the most frequently cited benefits of an MCP, but this does not appear to have been an important factor for the two demonstration sites. A variety of explanations are possible. Patients may not have perceived a greater emphasis on preventive care. Alternatively, patients may have valued this benefit less

than the significant financial incentives of participating in the demonstration. Another possibility is that patients considered coverage of preventive services to be a financial benefit (i.e., they received preventive services prior to the demonstration, but had to pay out-of-pocket for them).

Health Care Providers and Services

Patient satisfaction with dialysis staff and facility, and medical team appeared to be very high among both demonstration and comparison groups. The demonstration patients reported few differences in satisfaction with their health care providers and their dialysis facility after 1 year of enrollment. This is not surprising, as many of the demonstration patients did not change dialysis facilities after enrolling in the demonstration. Therefore, we did not expect any significant differences in satisfaction toward the health care team or dialysis facility from the demonstration patients at the 1 year followup.

In contrast, there were some very large and statistically significant differences in patient satisfaction with health care providers and services between the demonstration and comparison groups, especially the FFS group. The matched FFS and NDMC patients reported significantly higher satisfaction with their dialysis staff compared with the demonstration patients. It is uncertain why these comparison groups would report higher satisfaction with their dialysis staff since they were recruited from mostly the same facilities as the demonstration patients. It is unlikely that the dialysis staff would have treated demonstration patients differently from FFS or NDMC patients within the same facility.

Another significant difference was that, compared with demonstration patients, FFS patients reported higher satisfaction

with the ease in obtaining appointments with their primary care doctor and obtaining referrals to a specialist. This supports the commonly reported disadvantage of an MCP, namely, difficulty in gaining access to a primary care doctor or specialist (Reschovsky et al., 2000). In addition to higher satisfaction with access to their physicians, FFS patients also reported higher satisfaction with the availability of social workers and dietitians. A possible explanation for this observation is that under an MCP, there may be the perception of restricted access (through referral requirements). FFS patients also reported greater satisfaction with the ability to get to and from their dialysis facilities.

Although FFS patients reported higher satisfaction with their health care providers, they appeared to be less satisfied with their medical care when hospitalized compared with demonstration patients. It is unclear why these differences would be observed, but it may be a reflection of the more comprehensive hospitalization coverage provided under MCPs. Additionally, the demonstration plans provided a comprehensive case management approach, which may have resulted in better coordination of care among physicians, dietitians, social workers, and other specialists when patients were hospitalized. This coordinated care would seemingly provide greater comfort to the demonstration patients during a time when they are not in good health and receiving treatment in a large unfamiliar health care system.

Quality of Life

Results from our quality of life analyses address a key evaluation question of the demonstration: Does enrollment in managed care rather than traditional (i.e., FFS) programs affect the quality of life experienced

by ESRD patients? Quality of life measures are increasingly being recognized as important indicators of health, emphasizing the importance of the question.

The results presented here touch on several quality of life issues. First, these analyses assess whether or not baseline differences exist among those ESRD patients choosing to enroll in the demonstration as compared with a nationally representative sample of patients. Second, baseline quality of life was compared between managed care patients and the FFS and NDMC samples, which were matched on age, race, and time on ESRD. Differences between the first and second sets of comparisons can indicate differences in quality of life resulting from characteristics other than the ones matched for. Finally, our results explore changes in quality of life over time.

Quality of Life at Baseline

Results of the analyses comparing baseline quality of life of hemodialysis demonstration patients to that of DOPPS patients in California and Florida provide evidence that demonstration patients in these two States were healthier than a cross section of all hemodialysis patients in these service areas. At baseline, demonstration patients had higher physical and mental component summary scores. These differences were statistically significant at $p < 0.05$, but they were not clinically meaningful as determined by the criterion of a ≥ 3 -point difference (Samsa et al., 1999; Hays and Woolley, 2000). Furthermore, adjusted results indicate that demographic and comorbidity factors (including age, sex, race, coronary artery disease, peripheral vascular disease, and hypertension) accounted for all of the difference in baseline quality of life scores.

Matched Comparisons

Baseline quality of life comparisons were also conducted to compare physical and mental component scores of demonstration patients with the matched FFS and NDMC samples. With the exception of the physical component score among the NDMC sample, there were no differences in quality of life scores between demonstration patients and the two matched comparison samples.

The higher physical component score among NDMC patients may indicate that patients who had been in managed care for some period of time (NDMC patients) were healthier and had better physical quality of life than patients who opted for managed care at baseline. However, since this difference does not appear to be clinically significant, further work would be necessary to determine whether there is indeed any benefit of MCPs over time.

Changes in Quality of Life

Longitudinal analyses that assess changes in quality of life and other health indicators over time are especially crucial for evaluating the success of managed care models for ESRD patients. The results showed some statistically and clinically significant changes in quality of life scores among demonstration patients between baseline and followup. Nearly every subscale of the physical and mental component scores either improved or stayed approximately the same after 1 year. For three of these subscales—bodily pain, mental health, and role-emotional—the improvement is statistically significant as well as clinically meaningful. The overall mental component score also showed a statistically significant

increase. These results are striking because ESRD patients, due to the chronic nature of their illness, typically exhibit deteriorating quality of life over time. Indeed, when we examined a sample of DOPPS patients over a 1-year period of time, we observed a decrease in score among all of the subscale components as well as the two summary scores. Five of the scores (physical functioning, bodily pain, physical component score, social functioning, and vitality) showed statistically significant declines.

There are several factors that likely accounted for the higher mental component summary scores among the demonstration patients after 1 year in the demonstration. The financial benefits of the demonstration plan, resulting in less financial burden and stress to the patients and their families, may have been the primary factor. The higher scores may also have resulted from the better coordination of care from the case managers assigned to patients on enrollment, which was an essential component of the demonstration program. The basic functions of the case managers included initial screening, assessment, care planning, service provision and/or referral, monitoring, and reassessment. This level of service integration and case management likely provided greater assurance and comfort to ESRD patients.

CONCLUSIONS

The patient satisfaction and quality of life analyses presented here have important implications for evaluating the success of CMS' managed care demonstration. We observed that patients in MCPs are less satisfied than FFS patients about their access to health care providers. However,

demonstration patients clearly expressed greater satisfaction with the financial benefits provided under the plan, primarily the coverage of copayments, prescription drugs, and nutritional supplements. This greater satisfaction with the demonstration health plan benefits may partially explain the finding that mental quality of life scores increased after a year for patients enrolled in the demonstration. The statistically and clinically significant increase in quality of life scores for demonstration patients after a year in the MCP is striking and may indicate potential value in managed care approaches for ESRD patients. As quality of life indicators have been shown to predict morbidity, hospitalization, and mortality in dialysis patients, this is a result worthy of careful consideration.

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