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Staff-assisted home hemodialysis in debilitated or terminally ill patients

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Abstract. End stage renal disease (ESRD) patients who are diagnosed to have a terminal illness or severe debility have limited options for their continued care. This results in a frequent decision to withdraw dialysis support. Due to their tenuous condition, continued transportation to the dialysis facility further aggravates the emotional, financial and physical burden to the patient and family. We would like to present our data on 28 patients with severe debilitating and terminal illnesses. The mean age was 69 years with a (±) 11.8 SD and range of 44–87 years. Nine of them were males and 19 females. All of these were considered terminally ill as most of these patients had multi-organ failure. Ten had stroke, 16 had cardiac failure, 2 had severe vascular insufficiency, one resulting in bilateral leg amputation, 5 had debilitating pulmonary disease needing oxygen therapy and 8 had cancer. These patients were dialyzed at their home by a registered nurse (RN) according to a dialysis prescription provided by an attending nephrologist. Twenty-three patients died at home, one transferred to acute care facility and 3 to hospice care after a mean staff-assisted home hemodialysis (SAHD) duration of 14.1 ± 2.9 weeks. ESRD patients with severe disability can continue dialysis in a more convenient and comfortable setting at home, and yet be relatively cost-effective.

Key words: Ambulance costs in ESRD, Dialysis of dying patients, Transportation costs

Introduction

Comorbidities increase as the mean age of ESRD patients' increases. This results in increased rate of hospitalization and increased cost of care. There are many ESRD patients who do not meet hospital admission criteria and yet are too ill or debilitated to commute easily to their dialysis facility. The physical, financial, social and psychological difficulties contribute to their decision to withdraw from continued dialytic therapy. Those who commute to the dialysis facility in an ambulance or those admitted to the hospital add extensively to the cost of dialysis. Ambulance transportation significantly contributes to the total cost of care of the ESRD patients. We present the data of 28 patients, who were either thought to be terminally ill or severely disabled and could not be transferred to the dialysis facility without significant difficulty physical discomfort. We analyzed the cost of their medical care.

Patients and methods

Patients

All the patients were referred from dialysis centers in the greater Houston and surrounding area with a radius of approximately 100 miles. Some of these patients were directly referred from acute care facilities. Few of these patients were identified to have a debilitating illness while receiving In-Center Hemodialysis (ICHD) and hence referred for SAHD. These patients were too sick to commute / transfer to a dialysis unit, but their problems were not acute enough to meet the requirements for hospitalization. Once the patient was found to have difficulty in commuting or transferring to the dialysis facility, the patient was referred for SAHD. This decision was usually taken by the treating nephrologist. If the terminally ill patient is also diagnosed to have ESRD, no attempt was made to place a permanent vascular access, but was dialyzed after placing a cuffed catheter.

Patient demography

Twenty-eight patients were referred in 3 years from 1995 to 1998. Their mean age was 69 ± 2.22 (range 44–87) years. Nine of them were males and 19 females. Thirteen of these were African-Americans, 13 Caucasians and 2 Hispanics.

Comorbidities

Thirteen of these patients were diabetics and 19 were hypertensive. Diabetes mellitus was thought to be the cause of renal failure in 12 patients, hypertension in 4, chronic glomerulonephritis was recorded as the cause in 2 patients, renal failure secondary to multi-system failure in 7 patients, lupus nephritis in 2 and one patient had autosomal dominant polycystic kidney disease. Ten patients had a debilitating cerebrovascular accident, 5 had chronic respiratory failure requiring continuous oxygen supplementation, and 16 had severe cardiac failure of which 4 were identified as New York Heart Association (NYHA) class IV, two had atherosclerotic vascular disease, one had traumatic spinal paralysis and eight had metastatic cancer. Fourteen of these patients had three or more organ system involved (Table 1).

Staff assisted home hemodialysis (SAHD)

Once it was determined that the patient met the criteria for SAHD, the patient was referred to the *Quality Dialysis Incorporated* (QDI). QDI would then interview the patient and family, inspect the residence and assess if the patient qualified for SAHD. The inclusion criteria included a clean and secure place for residence and availability of space to house the hemodialysis machine. Most of these patients needed added financial support or insurance to cover the cost of SAHD, while Medicare paid the customary capitated fee. All these patients were identified unsuitable for transfer to dialysis center by wheelchair hence could not be transferred in a wheelchair-van. Upon acceptance, the registered nurse (RN), social worker and dialysis technician would explain the procedure, educate the patient and family, and set out practical goals. Necessary structural and plumbing modifications were made and the dialysis machine installed after obtaining an informed consent. In most instances Fresenius 2008 H machines and Fresenius F-80 dialyzers were used. There was no re-use of the dialysis cartridges. The dialysis was performed according to the prescription of an attending nephrologist and followed the dialysis outcome quality initiative (DOQI) guidelines. As most of these patients require medication administration, only a certified RN performed the dialysis procedure. Monthly, bimonthly and quarterly investigations are carried out as per the DOQI guidelines, and the results conveyed to the attending nephrologist. The first multi-disciplinary patient care conferences (PCC) was held within 10 days of the initiation of SAHD and subsequent multi-disciplinary PCCs were conducted as per the requirements of the Texas Department of Health (TDH) and all the health care issues relating to the patient discussed. Upon discharge from the hospital, the nephrologist determined the frequency of patient visits. The nephrologist made home visits as most of the patients were non-ambulatory and/or had difficulty in transportation. In most cases, the patient was examined every month and regular discussions were held with the patient and the family. As feasible, the same RN performed the treatments to maintain the continuity of care and rapport.

Results

Although most of the patients fell in the geriatric age group (>65 year), 9 were below 65 years of age. Sixteen of these had severe cardiac failure and 4 were identified as class New York Heart Association (NYHA) class IV. Ten had cerebrovascular accident, 8 had cancer and 2 had systemic lupus erythematosus. The mean age was 69 ± 2.22 (range 44–87) years, and the mean dialysis duration was 14.05 ± 2.89 weeks (range 2–71 weeks). The mean hospitalization days were 9.43 ± 1.83. Despite their illness or debilitated state, 10 patients did not require hospitalization, and among those hospitalized, 5 required <10 days of hospital stay. Twenty-three patients died and in one patient the dialysis was electively withdrawn. Two were transferred to hospice care, one transferred to an acute care facility and died, while one was transferred back to chronic care facility due to problems with his insurance coverage.

Cost analysis

The cost of a bed in our area is approximately $585 per day or $4095 per week. The in-hospital dialysis cost is $373 per treatment of which $246 is direct cost. The indirect costs such as the costs of dieticians, secretaries, resident physicians and administrative costs make up another $127 per treatment making the total cost to approximately $1119 per week. Therefore the total dialysis and hospital bed cost approximates

Table 1. Demography of the patients

Number	Age	Race	Sex	Etiology	Comorbidity	Weeks	Hosp Days	Result
1	62	B	F	CGN	CHF, COPD, Pul Fail	47	22	Died
2	75	W	F	MSF	NEO	3.5	0	Died
3	78	B	F	DM	MSF, HTN	6	0	Term
4	59	B	F	DM	CVA, MSF, HTN	4	7	Died
5	82	B	F	DM	CVA, MSF, HTN	8	21	Died
6	76	B	M	MSF	CHF, COPD, Pul Fail	4	0	Hospice
7	64	B	F	DM	CHF, HTN	9	15	Died
8	83	B	F	DM	CVA, HTN	15	10	Died
9	81	W	M	MSF	CHF	7	0	Died
10	44	W	F	SLE	NEO	25	20	Died
11	65	B	M	DM	CHF, NEO, HTN	8	1	Tr. chr. Care
12	68	L	F	DM	HTN, NEO	30	16	Died
13	80	W	F	MSF	NEO	7	28	Died
14	64	W	F	DM	CHF	9	31	Died
15	87	W	M	HTN	CHF, CVA	14	15	Died
16	45	W	F	DM	CHF, COPD, Pul Fail, HTN	7	13	Died
17	73	B	M	DM	PVD, HTN	26	0	Died
18	64	B	M	DM	HTN, CVA	4	0	Died
19	69	B	F	DM	HTN, CVA	7	20	Died
20	70	W	F	HTN	CVA, CHF	9	3	Died
21	46	B	F	SLE	DM, CVA	14	8	Died
22	78	W	M	HTN	CHF, CVA	71	6	Died
23	72	W	M	CGN	CHF, Pul Fail, HTN	16	0	Tr, ac care
24	84	B	F	MSF	CVA, MSF	2	0	Hospice
25	53	B	F	MSF	NEO	2	0	Died
26	76	W	M	MSF	NEO	1	18	Died
27	72	W	F	HTN	CHF, Pul Fail	28	10	Died
28	68	W	F	ADPKD	NEO, HTN	8	0	Died

The demography of the patients with the comorbidities, duration of SAHD, hospitalization days and outcomes.
Abbreviations:
CGN = Chronic Glomerulonephritis; ADPKD = Autosomal Dominant Polycystic Kidney Disease;
MSF = Multi System Failure; CVA = Cerebrovascular Accident; DM = Diabetic Mellitus;
CHF = Congestive Heart Failure; HTN = Hypertension; NEO = Neoplasm;
SLE = Systemic Lupus Erythematosus; Pul. Fail. = Chronic Respiratory Failure;
Tr ac care = Transferred to acute care facility; Tr chr care = Transferred to chronic care facility.

$5214 per week. However, there is a wide variation in the hospital bed cost as well as the in-hospital hemodialysis cost in our region. Whereas if the patient is transported from his house to the nearest dialysis facility by an ambulance, the ambulance cost alone can be as much as $375 for one way ride, making the transportation costs of $750 per treatment and $2250 per week. The In-Center Hemodialysis (ICHD) dialysis cost approximately $130 (Medicare reimbursement) per treatment making the weekly dialysis cost of approximately $390. Hence the total weekly dialysis cost and ambulance cost adds up to $2640. The SAHD costs are approximately $400 per treatment or $1200 per week (Table 2). This was paid by the third party payer after Medicare paid the customary capitated fee. This does not include the set-up costs such as the required plumbing and structural modifications, which are one-time costs amounting to $400 to $650.

Discussion

Home hemodialysis (HHD) patients have significantly better survival rate, better quality of life, increased independence and better rehabilitation, than peritoneal dialysis (PD) or in-center hemodialysis

Table 2. Weekly Costs of IHHD, ICHD and SAHD

In-Hospital Hemodialysis				
Cost of bed	:	585 × 7	=	$4095
Dialysis cost (246+127)	:	373 × 3	=	$1129
Total cost per week	:			$5224
In-Center Hemodialysis with ambulance transportation				
Ambulance cost	:	~375 one way		
Weekly ambulance cost	:	375 × 6	=	$2250
Weekly dialysis cost	:	130 × 3	=	$ 390
Total costs per week	:			$2640
Staff Assisted Home Hemodialysis				
~ $400 per treatment × 3/Week	:			$1200

(ICHD) patients do [1–5]. In general they tend to be younger and have less comorbid illnesses. When comparison was made between age, gender, race, diabetes and comorbid conditions matched HHD and ICHD patients using Cox proportional hazards model, there was 44% less relative risk of death in HHD patients (RR = 0.56 P = 0.02) [1]. Home hemodialysis used to be the predominant form of dialysis modality in the United States when the Medicare program for ESRD began in 1973. At that time more than 40% of approximately 11,000 dialysis patients received HHD as it was found to be very efficient and cost-effective [6]. It was also observed that paid HHD helpers were more useful than a paid family member or friend [7]. Although significant variations existed, but on an average HHD cost inclusive of the aide payment, was 77–82% of ICHD cost [8]. This showed HHD was cost-effective even after paying an aide. In 1983 Congress introduced composite rate reimbursement, which pays the same for ICHD and HHD, but excludes the payment for HHD aide. Now HHD programs using aides have to pay them separately which may be one of the reasons of the decline of HHD in the United States to an extent that currently less than 0.8% of dialysis patients receive HHD [9].

Investigators for the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment (SUPPORT) group suggested that older patients with severe debilitating illness receive fewer procedures, fewer life sustaining treatments and medical care that is less costly than younger patients do [10, 11]. The psychosocial stress due to the terminal illness is reflected on the whole family. Studies also have reported that up to one third of spouses of terminally ill patients have depressive symptoms [12–14]. The economic burden over the family is also immense. The SUPPORT group reported that in 20% of the families of terminally ill patient a family member had to stop working; and 31% of the families had lost most of their savings. A study on understanding the economic and other burdens of terminally ill patients and their care givers, observed 44.9% patient with substantial care needs reported a subjective sense of economic burden. The patients or their families had to take out a loan or mortgage, spend their savings or obtain additional job. These patients are more likely to consider euthanasia or physician assisted suicide [15]. With an increase in the aging ESRD population on dialysis, nephrologists will, more frequently, face this dilemma of appropriateness of the aggressive management. Those ESRD patients, who are confined to bed due to severe debilitating illness or a terminal illness, need either remain confined to hospital or be transported to the dialysis facility by ambulance. Both these options are cost prohibitive. Currently ESRD treatment costs approximate 15.64 billion dollars annually, and the dialysis costs are $52,000 per patient per year [9]. The cost of care for a non-diabetic patient is approximately $48,000 per year, as compared to $57,000 per year for an average diabetic patient. This cost further increases to $63,000 per year when the age of diabetic patient is greater than 75 years [9]. These costs are further likely to increase with additional comorbidities especially when these patients are hospitalized for conditions that can be managed as an out-patient. A survey conducted by the Health Care Financing Administration of the U.S. Department of Health and Human Services (HCFA) of the dialysis facilities revealed that more than 35% of the patients had 2 or more comorbid conditions. The Medicare payments for 1997 transportation cost for the dialysis patients is estimated to be $942.68 per patient year at risk, which is exceeded only by nephrology, pediatric medicine, and medical supply company costs of $2154.47, $2497.74, and $1148.28 respectively (Table 3). The total yearly Medicare payments towards transportation has increased from $96 Million to $195 Million in just 7 years from 1991 to 1997, and currently is estimated to be close to $200 Million [16] (Figure 4). This is not surprising as the USRDS data from 1997 reveals that 5% of the dialysis patients use ambulance as their mode of transportation to the dialysis unit (Figure 5) [17].

The financial burden is not only restricted to dialysis costs but also indirectly to family time, home help and visiting nurses costs etc. Most of the family members devote time to their work on dialysis days while the dialysis nurse attends to the patient. Simi-

Table 3. The Top 10 Medicare Payments per Patient Year at Risk by Physician/Supplier Specialty and Year

Specialty	1993	1994	1995	1996	1997
Total	**9131.03**	**8849.57**	**9254.13**	**9889.59**	**10014.58**
Nephrology	1931.85	1876.15	1938.89	2205.12	2154.47
Pediatric Medicine	2071.21	2481.22	2562.06	2718.46	2497.74
Medical Supply Company	722.30	861.47	1005.79	1076.28	1148.28
Laboratory	858.36	855.17	898.29	948.90	924.53
Ambulance Service Supplier	**860.34**	**911.08**	**930.37**	**926.03**	**942.68**
Internal Medicine	649.34	597.89	648.75	742.37	737.00
General Surgery	636.24	625.98	671.70	645.62	626.55
Radiology (Diagnostic & Therapeutic)	319.33	334.64	395.02	434.80	439.35
Cardiology	278.49	283.31	303.67	317.36	334.44
Anesthesiology	288.00	269.72	283.78	292.87	310.85

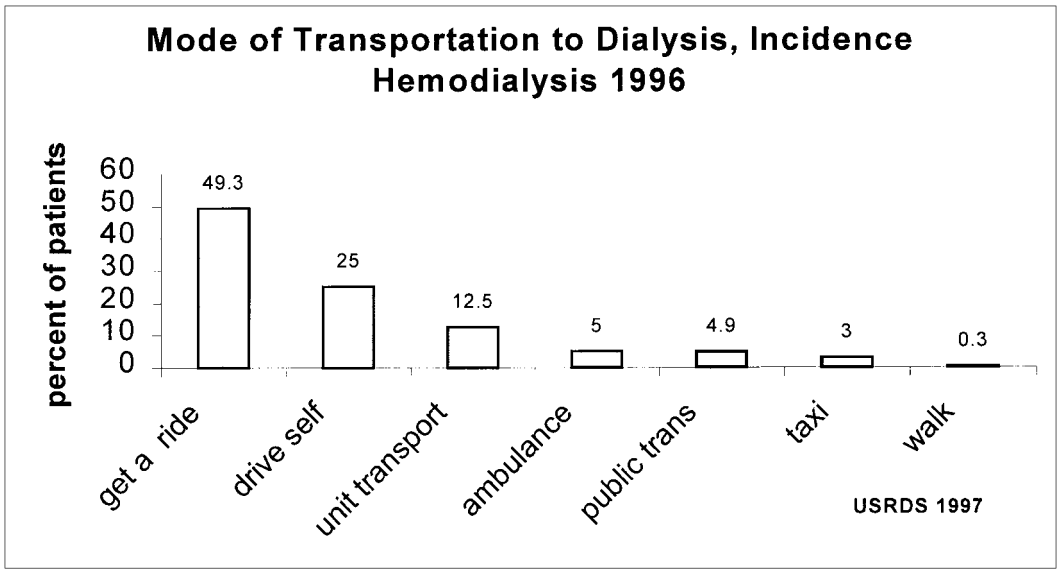

Figure 1. Mode of Transportation.

larly the services of the visiting nurse and home help may also be avoided while the dialysis nurse is present. Apart from financial gains, the alleviation of physical discomfort and psychosocial distress from hospitalization can significantly add to quality of life as was expressed by many of these patients.

In summary SAHD has an important role in the management of ESRD patient and this modality like HHD is neglected and underutilized. It not only is cost effective in severely debilitated and terminally ill patients, but also may decrease the emotional, financial and physical burden to the patient and family and therefore should be considered as an option in these patients.

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