Knowledge of Home Dialysis Among Inner-City Satellite Hemodialysis Patients

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There is limited use of home renal replacement therapies in the U.S.A. One percent of dialysis patients are on home hemodialysis (HHD) and only 9% undergo peritoneal dialysis (PD). In an effort to better understand this, 161 satellite hemodialysis patients in 6 units in Brooklyn were surveyed. Forty-eight percent of patients were women, 86% were black, 5% white, 8% Hispanic, and 1% other. Mean age was 49.4 years (range 22 – 69 years). Etiology of renal disease was hypertension (41%), diabetes mellitus (31%), polycystic kidney disease (3%), systemic lupus erythematosus (4%), and other or unknown (21%). Patients were queried about knowledge of and attitudes toward home therapies. Seventy-nine percent of patients knew of home dialysis. The source of this information was the nephrologist (59%), the social worker (14%), a nurse (8%), other patients (4%), and other sources (15%). Only 10% of patients had ever considered HHD. Fifty-four percent were afraid to do self-care at home and 35% were not interested. Surprisingly, only 3% felt they had no reliable helper and 8% felt that their housing was not suitable. Similarly, 78% of patients had been spoken to about PD, but only 11% had considered it. Forty-one percent were afraid of doing self-care on PD, and 45% were not interested. We conclude that, although the majority of patients in six inner-city dialysis units had heard of home dialysis, only a small number ever considered it. As many patients were afraid of doing home therapy, better education about the risks and benefits needs to be disseminated.

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Key words

Home hemodialysis, peritoneal dialysis, modality selection, urban, inner city

Introduction

Home dialytic therapies, including home hemodialysis (HHD) and peritoneal dialysis (PD), account for a very small number of patients being treated for end-stage renal disease (ESRD). According to the 2001 United States Renal Data System (USRDS), in 1999 the percentage of patients being treated by HHD and PD in the United States was less than 1% and 9% respectively [1]. Before Medicare assumed the cost for ESRD treatment in 1973, HHD was performed by 40% of patients on dialysis. Home HD is associated with better survival and rehabilitation than in-center treatment [2]. In addition, several studies have suggested that the survival of patients on PD is at least equivalent to that of patients on in-center dialysis and, in some cases, superior [3,4]. A recent survey of American nephrologists revealed that they believe home dialytic therapies are underutilized in this county [5]. In view of this and the better survival and rehabilitation offered by home therapies, it is not clear why more patients in the U.S.A. are not treated by these modalities. In an effort to understand why patients do not pursue home dialysis, we surveyed patients undergoing center hemodialysis in six dialysis units in an urban inner-city area.

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Methods

The study was approved by the Institutional Review Board. Questions about knowledge of and attitudes toward home dialysis were part of a larger survey examining reasons why chronic in-center dialysis patients were not on a transplant list. A 25-item questionnaire was used to interview randomly selected patients in six dialysis units in Brooklyn, NY. These six units include five not-for profit and one for-profit unit. Examples of the questions are shown in the Appendix. English-speaking patients seated in alternate chairs were approached. If they were willing and met inclusion criteria, they were personally interviewed (see below). Only 5 patients refused to participate. In addition, patients on the evening shift (after 1600 hours) were not interviewed. Patients were excluded if they had been on dialysis less than 6 months (to give them time to adjust to therapy), if they had HIV disease or active malignancies, or were undocumented aliens with no insurance coverage. Those conditions potentially make patients unsuitable for home dialysis or transplantation. The questionnaire was administered orally by a renal fellow or a medical resident under the supervision of an attending nephrologist. Each interview took approximately 1 hour.

Statistical analysis was performed in the following way: All data were entered into SPSS software (SPSS Version 8; SPSS Inc. Chicago, IL, U.S.A.). Descriptive data were analyzed for group mean and standard deviation. Categorical data were tabulated and percentages reported.

Results

One hundred sixty-one patients answered the survey. The demographic data of the patients are given in Table I. Eighty-six percent of the patients were black, 5% white, 8% Hispanic, and 1% other. There were 84 men and 77 women. Mean age

of the patients was 49.4 years (range 22 – 69 years). The major cause of renal disease in this group was hypertension (41%); 31% had diabetes, 3% had polycystic kidney disease, 4% had systemic lupus erythematosus, and the remaining patients were classified as glomerulonephritis, unknown, or other.

Two patients were excluded because they were uninsured; 67% of patients had Medicare as their primary insurance, 21% had Medicaid, and 12% had private insurance. The self-reported annual income of the patients is shown in Table I. The mean number of years of formal education was 11.9 ± 0.24 years. Approximately one third of the patients had not graduated from high school (Table I).

Nineteen (12%) patients had had no pre-dialysis care. The majority (37%) received their pre-ESRD care from a primary-care physician; 22% were under the care of the nephrologist currently treating them; 24% were treated by another nephrologist; and 5% were seen by other medical specialists. Thus, more than half the patients (54%) did not have routine care by a nephrologist until they required dialysis.

Seventy-eight percent of patients were aware of HHD, but only 10% had ever considered it. The reasons given for not performing HHD were the following: fear of self-care (54%), not interested (35%), no available partner (3%), and no suitable home (8%). The same number of patients were aware of PD (78%), and 11% had considered it. Forty-one percent of patients said they were afraid of performing self-care on PD, and 58% were not. When questioned about interest in PD, 45% of patients were not interested in the therapy, but 55% expressed some interest in it. Two percent of patients felt they had a medical contraindication to successfully performing the treatment.

TABLE I Demographic data (n = 161).

Characteristic	N *(%)*
Mean age (years)	49.4 (range 22–69)
Gender	
Male	84 (52)
Female	77 (48)
Race	
Black	138 (86)
Caucasian	8 (5)
Hispanic	13 (8)
Other	2 (1)
Etiology of ESRD (n=160)	
Hypertension	65 (41)
Diabetes	50 (31)
Polycystic kidney disease	5 (3)
Systemic lupus erythematosus	6 (4)
Unknown or other	34 (21)
Education (n=158)	
Elementary school	19 (12)
Some high school	32 (20)
High school graduate	58 (37)
Some college	25 (16)
College graduate	16 (10)
Some graduate school	8 (5)
Primary insurance	
Medicare	108 (67)
Medicaid	34 (21)
Other	19 (12)
Annual income (n=160)	
<$20,000	116 (72)
$21,000–$40,000	38 (24)
$41,000–$60,000	4 (3)
>$60,000	2 (1)

It is interesting to examine the source of the patients' information regarding home dialysis. Fifty-nine percent said their doctors told them about it. Only 14% were told about home dialysis by the social worker, 8% by a nurse, 4% by other patients, and 15% were made aware of home dialysis by other sources, including news and television.

Discussion

In the treatment of ESRD, most nephrologists agree that a well functioning transplant is the ideal therapy [6]. If this is not available, nephrologists believe that home therapies are preferable to in-center treatment and are underutilized. Mendelssohn *et al.* surveyed members of the National Kidney Foundation Council on Dialysis to assess the attitudes of American nephrologists about modality selection. The 47% of nephrologists responding felt that HHD and PD were underused [5]. Home HD, while technically more difficult, has been shown in several studies to have better survival and rehabilitation than in-center dialysis. Woods and co-workers studied center and HHD patients and found that the relative risk (RR) of dying on home dialysis was 0.37 [95% confidence interval (CI) 0.22 – 0.60]. Even after correcting for age, diabetes, and comorbid conditions, patients on home dialysis were still significantly less likely to die than their in-center counterparts (RR 0.58, 95% CI 0.35 – 0.95) [7]. Several studies have suggested that PD offers at least equivalent survival to in-center hemodialysis and may be preferable, particularly during the first few years of dialysis [3,4,8].

Despite this, home therapies are the treatment for only 10% of the ESRD population. The reasons for the decline in HHD, once performed by 40% of all dialysis patients in the pre-Medicare era, have been reviewed by Delano [9]. The factors considered in the near demise of HHD are the following: the proliferation of satellite units once Medicare began covering dialysis patients, the aging of the dialysis population, the greater comorbidity that patients have, and the rise of chronic ambulatory PD.

The reasons for the more recently occurring decline in PD have been examined less and are less clear. Concerns about the long-term role of PD once residual renal function declines may prevent nephrologists from proffering the therapy. The relatively small number of patients on either of the home therapies, and the small number of dialysis centers that offer HHD, may limit nephrology trainees' exposure to these treatments.

In our survey of in-center patients in six dialysis units in Brooklyn, we found that, while 78% of patients were aware of home dialysis, many were afraid of performing self-care at home.

Patients being treated at these units come from a variety of sources. The extent of pre-dialysis education given in the

renal clinics at the hospitals associated with these units is variable, with no formal programs. Several of the hospitals in Brooklyn now have a pre-dialysis educator sponsored by industry, and it remains to be seen if more patients will select home modalities in the future [10]. In addition, 54% of the patients surveyed did not see a nephrologist before developing ESRD, so it is unlikely that they received adequate education about different modalities. Studies have shown that when patients receive pre-dialysis education about modality choice, a higher percentage choose to undergo PD [11]. Federal guidelines state that patients must be made aware annually of options in home therapies and transplantation [12]; however, we do not know how vigorously this is followed.

As our survey was conducted in the inner city, the majority of our patients were minorities, with 86% black and 8% Hispanic. Also, 96% of our patients had a self-reported annual income of less than or equal to $40,000. While black patients have superior survival to whites on all forms of dialysis, black patients are less likely than whites to either select or be offered PD. In 1999, 71% of new PD patients were white and 19% were black [1]. Can the black inner-city resident do as well on home dialysis? A study of incident patients in a large urban PD unit with 61% black and 12% Hispanic patients examined ethnic differences in survival. The RR of mortality for white patients compared to blacks was 2.35. The authors conclude that PD should be considered a viable option for black patients beginning treatment for ESRD [13]. We have previously shown that HHD can be successfully performed in the inner city. The mean survival of 133 middle class patients in our program was no different from that of 71 patients classified as indigent [9].

Urban inner-city areas have a unique set of problems that may be barriers to home dialysis, including small homes with inadequate plumbing and electricity and lack of a suitable helper. In a previous survey of inner-city residents, Joseph and co-workers found that lack of a helper and suitable home environment were the major reasons that a group of self-care patients did not go home [14]. Surprisingly, we did not find helper availability or an unsuitable home to be a major deterrent. Joseph's patients were a pre-selected group, as they were already performing self-care. Our major finding that disinterest or fear of treatment is responsible for the non-consideration or selection of home dialytic therapy in this group of patients is potentially amenable to change. Unfortunately, our survey did not address the specific reasons for the patients' fear of home treatment. Dialysis at home is as safe, if not safer than treatment in-center [9]. Corrective actions include disseminating the risks and benefits of the treatment to patients, having successful home patients serve as role models, and enlisting and educating the health-care professionals (*i.e.*, nurses, technicians, social workers) that see the patients frequently in the recruitment of patients.

Our study is flawed by the following: There may be selection bias. Persons dialyzing on the evening dialysis shifts were not interviewed. It is possible that working patients who are potentially more interested in home therapies are more likely to select those shifts. Patients may have recall bias as to whether or not they were spoken to about home dialysis and who spoke with them. As we did not specifically ask, we have little information about the pre-dialysis education patients received. Finally, as our units were all in the inner city, we do not know if the same results would be found in rural or suburban areas.

Conclusion

We found that approximately 80% of patients dialyzing in six inner-city units in Brooklyn were aware of HHD and PD. A small percentage, 10% and 11%, had considered going home on hemodialysis or peritoneal dialysis, respectively. The major deterrents to considering home dialysis were fear of performing treatment at home and disinterest. An educational program detailing the risks and benefits of home dialysis for staff and patients may help overcome some of the barriers to treatment at home. Finally, newer strategies for home hemodialysis, including short daily dialysis with user-friendly machines and nocturnal dialysis, may also increase the number of patients performing home dialysis [15].

Appendix

Has anyone spoken to you about peritoneal dialysis? Yes=1, No=0
Home hemodialysis? Yes=1, No=0
If yes, where did you get the information?
1. Nephrologist
2. Social worker
3. Nurse
4. Other patient
5. Other (specify)

Did you ever consider peritoneal dialysis? Yes=1, No=0
If not, why not?
1. Medical contraindication
   a. Cardiovascular disease
   b. Psychiatric illness
   c. Overweight
   d. Abdomen not suitable (previous surgery, hernia, *etc.*)
2. Not told about it
3. Afraid of doing self-care
4. Not interested

Did you ever consider home hemodialysis? Yes=1, No=0
If not, why not?
1. Medical contraindication
   a. Cardiovascular disease
   b. Psychiatric illness
   c. Poor vascular access
2. Not told about it
3. Afraid of doing self-care
4. Not interested
5. No helper available
6. Living quarters not suitable
7. Too expensive

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