

The *Nephrology Nursing Journal* Celebrates 50 Years!

Home Dialysis, Is It Worth It?

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The topic of home dialysis has been a significant area of interest over the years. A review of the literature reveals numerous studies and papers done on the subject, but the foci were limited in many cases to one or several specific areas, such as rehabilitation, stress, finances, and psychological impact. A search of the literature revealed that home dialysis provides for better rehabilitation,¹⁰⁻²⁻⁸⁻¹³ reduced risk of hepatitis,³ more independence,³⁻¹² freedom to conveniently schedule dialysis³ and decreased treatment cost.³⁻¹⁻⁵ Disadvantages listed include psychological stress to patient and family,⁶⁻³ anxiety over mechanical failures,³ personal sacrifices required of the helper⁴ and difficulties in closely following and assessing patient's fitness and needs due to infrequent contact after the training phase.

Because of our large, diversified, home patient population, it was felt that a study encompassing many aspects of home dialysis was feasible. The purpose was to get an overall view of home dialysis. Areas of study include: 1) patients' and partners' reactions to home dialysis as a mode of treatment for end stage renal disease, the pros and cons; 2) patients' rehabilitation and employment status of partners; 3) feasibility of continuing home training programs; 4) the strengths and weaknesses of our past and present training programs; and 5) the common stress factors of home dialysis as identified by those participating in the home program.

HISTORY OF OUR PROGRAM

Although our present center is only one year old, the original program dates back to 1966 when the Artificial Kidney Center was established. The patients included in this study include those trained at the Atlanta Artificial Kidney Center, the Atlanta Regional Nephrology Center, which opened in 1970, and Dialysis Clinic, Incorporated, since these centers have been run and staffed by basically the same medical personnel. Dialysis Clinic, Incorporated has assumed follow-up care of patients trained for home dialysis by the three programs. As of November, 1975, the total program had treated 394 patients by dialysis and/or transplant. A total of 213 patients have been home trained with 19 returning to in-center dialysis. 82 remained on home dialysis.

PAST TRAINING PROGRAM

Since the start of our program in 1968, the philosophy, length, and methods of teaching have changed considerably. The early training program was indefinite in length and basically unstructured. The patient trained first and then trained his partner. The training program usually lasted 3 months. No written procedures were available for the couples to use. In 1970, the course was shortened to 8 weeks and the patients and partners were taught together



Editor-In-Chief Note: ANNA's journal, first published in 1974 was using the title, *The Journal of the American Association of Nephrology Nurses and Technicians*, and is now titled, the *Nephrology Nursing Journal*. Throughout our 50th year of publication in 2023, we will be sharing excerpts and information about our first 50 years here in NNJ and on social media (@NNJOnline). This article, "Home Dialysis, Is It Worth It?", was published in 1977.



with written procedures. The course was again shortened in 1972 to 4 weeks and a manual with the basic procedures was written and given to every couple.

PRESENT TRAINING PROGRAM

Since August of 1972, the home training course has routinely been 4 weeks in length. Some couples complete the course in 3 to 3½ weeks, while a very small number require 4½ to 5 weeks. Prior to beginning the program, a day is set aside for orientation and for the establishment of staff and patient relationships. Patients and partners are trained together in a structured course which consists of dialysis related activities 5 days a week; 3 dialysis days in which instruction is individualized, and 2 class days in which formal lecture, informal discussions and activities are utilized. The class days of the 4th week are left open for dealing with any problem areas that need to be covered. As much independence as can be handled by the couple is encouraged from the first week. The 4th week of the course consists of unassisted dialysis in order to simulate the home environment. Anatomy of dialysis, and activities are taught in depth through the use of a detailed manual, demonstrations and actual experience.

PROFILE OF PATIENT SAMPLE

Sixty-one patients, 74% of the total home dialysis population, were included in this study. The characteristics of the sample population are listed in Table 1.

Table 1: Profile of Patient Sample

<i>Age:</i>	Range = 13 to 66 years Mean = 40.25 years		
<i>Sex:</i>	Females = 27 Males = 34		
<i>Blood Access:</i>	Shunt	17	15%
	Bovine/Fistula	54	85%
<i>Years of Education:</i>	Range = 2 to 21 years mean = 11.6 years		
<i>Duration of Dialysis:</i>	3 to 110 months mean = 28.4 months		
<i>Duration of Home Dialysis:</i>	2 to 104 months mean = 25.5 months		
<i>Partners:</i>		<i>Machines Used:</i>	
Spouses	40	Drake-Willock	23 37.7
Husbands	17	Travenol Ams	15 24.5
Wives	23	Cordis Dialysystem	7 11.4
Daughter and Wife	1	Milton Roy	2 3.2
Mother and Father	2	Cobe Century I	1 1.6
Mother	10	Lifemed	13 21.3
Father	1		
Sister	1	<i>Dialyzers Used:</i>	
Child	4	Dow 4	12 19.6
Niece	1	Dow 4 ²	7 11.4
Friend	1	Dow 5	40 65.5
		Gambro	2 3.2

Thirty-four of the patients were male and twenty-seven were female. The mean age of the patients was 40.25 years, with a range of 13 to 66 years. Formal education ranged from 2 to 21 years, with a mean of 11.57 years. Duration of dialysis ranged from 3 to 110 months (mean = 28.4 months), while the duration of dialysis at home was from 2 to 104 months (mean = 25.5 months). Sixty-seven percent of the partners studied were spouses (see Table 1 for Profile of the Sample). It is interesting to note that the partner of one patient is the husband of a deceased home dialysis patient. He volunteered to dialyze the patient when her former partner (a friend) withdrew from the program. Dow dialyzers are used to treat 96.5% of the sample. Eighty-five percent require needle venipuncture.

METHODOLOGY

In most cases, patients, partners, and on occasion, other members of the family were seen in their own home environment. A questionnaire was devised as a guide. It was implemented in the form of unstructured conversations in order to encourage free flowing communication. The two authors of this paper were present during all interviews. As patients responded to the initial open-ended questions, remarks to encourage further discussion were made.

Specific data about home dialysis was collected and included the following: 1) degree of hardship, both financial and emotional, 2) social and emotional adaptation of the patient, partner, and family, 3) treatment time involved, 4) source of financial support for treatment, 5) stress factors involving technical and mechanical difficulties, 6) rehabilitation to a satisfying level of productive activity, 7) patients' and partners' assessment of home dialysis and their recommendations for improvement, 8) patients' responses regarding home dialysis versus their previous experiences in in-center dialysis, 9) feelings of both patients and partners about the idea of returning to in-center dialysis. Reasons for desiring or resisting return to in-center dialysis were also solicited.

Interviews were conducted during dialysis in the majority of the cases. The length of the interviews ranged from 45 minutes to 2 hours, averaging 1 hour.

RESULTS

Dialysis related time expenditure was found to be from 15 to 24 hours per week for those dialyzing thrice weekly for 4 to 6 hours each time. For those who dialyzed twice weekly, 10 to 16 hours were spent in dialysis related activities. It was found that most of the patients prepared the equipment while most partners cleaned up post-dialysis. Patients and partners noted that the long hours of dialysis were spent in numerous ways such as conducting business, watching television, reading, studying, visiting with family, and resting.

Thirty-six of the home patients were income-producing prior to the onset of end stage renal disease. Of these 36, 18 remain income-producing. Of the 8 patients who were full-time students prior to dialysis, 7 remain so. The 8th student graduated from high school after starting home dialysis.

For the purpose of this paper, those included under gainfully employed are homemakers, students, and income-producing persons. Ninety-two

percent of the total patients were gainfully employed prior to dialysis. Eighty-four percent of the total are gainfully employed now, though they may have changed categories.

Table 2: Rehabilitation

<i>Categories</i>	<i>Total No. Before</i>	<i>Total No. Now</i>
Patients:		
Income-producing	36	18
Students	8	7
Homemakers	12	26
Inactive	5	10
Partners:		
Income-producing	43	39

Findings reveal that 43 of the partners were income-producing prior to the beginning of home dialysis and 38 are income-producing now. One additional partner who was not employed prior to home dialysis is working now, bringing the total income-producing partners to 39.

All of the sample are under Medicare except one who has state coverage. Only 10 who are not eligible for financial assistance from insuring organizations are responsible for the remaining 20% of the dialysis cost. All of these cited a definite change in financial status. Forty-six percent of the families stated that they have experienced financial difficulties due to the cost of medicines, travel expenses to and from health care facilities, and work loss. To ease financial difficulties, most of the families are in favor of payment to the partners for their assistance and 100% coverage of home dialysis costs as provided for in bills which are in Congressional Committees at the present time.

When the question, "What causes you the most stress in home dialysis?" was asked, numerous replies were given. Needle insertion, machine problems, fear of complications, and blood leaks were the most frequently mentioned (Table 3).

Table 3: Stresses of Home Dialysis

Needle Insertions	15 of the patient population
Machine Problems	13 of the patient population
Fear of Complications	11 of the patient population
Blood Leaks	10 of the patient population
Stress on Family	8 of the patient population
Time Involved	10 of the patient population

When asked if they felt they were adequately prepared in home training to handle technical difficulties, 40 (65.5%) replied in the affirmative. Of those replying negatively, most were trained prior to 1972 when a structured

program and a detailed manual were not available. In spite of the stresses of home dialysis, only 9 (14.7%) of the patients and 12 (19.6%) of the partners stated that they would prefer in-center dialysis. The most common reason given by patients for preferring home dialysis was the comfort of their home environment and the attention received from the partners. Most partners preferring home dialysis stated that they felt the patient received better care and had more control over the dialysis. It was also felt that the patient had more opportunity to continue normal activities because of the flexibility of his schedule. The primary reason given by those patients who wished to return to in-center dialysis was to relieve the assistant of the responsibility and the inconvenience of dialysis.

Our study helped us to get an overall view of home dialysis from patients and partners and to pinpoint certain specific needs for home training and follow-up care.

DISCUSSION

Rehabilitation in this study is defined as returning to a satisfying level of productive activity. Even though 50% of our income-producing patients have not returned to employment, many have become full-time homemakers, freeing their spouses of home chores, or supplementing income resources with such activities as gardening or crafts. In a sample study conducted in our center of 50 in-center patients and this home patient population, we found that our home patients are more rehabilitated than our in-center patients. Home patients who did not return to employment gave many reasons for not doing so. They include the following: debilitation, unavailability of a job suitable to their limitations, lack of financial gain from employment, lack of motivation and preference. It is worth noting that many of those not employed now were manual laborers who were limited physically after starting dialysis. Vocational Rehabilitation is available to many of our patients to assist them in gaining new skills. This may permit them to once again become employable. We have come to agree with both Sullivan¹² and Springer¹¹ that expecting patients to continue full-time employment while performing home dialysis is expecting them to do two jobs at once. Dialysis does qualify as work by anyone's definition. Dialysis is a job that is mentally stressful and it requires technical skill and physical exertion. It is a job that requires more mental effort and technical qualifications than most. Home dialysis time requires from 10 to 24 hours each week. Home dialysis, because it is work, qualifies our patients as part-time workers. It is interesting to note that in spite of the time and effort involved in home dialysis, most of the partners continued full-time employment.

What do these ideas about rehabilitation of home dialysis mean to those of us working in their field? They have several implications. First of all, we, like Sullivan, feel that we must be cautious about turning our patients into "a reflection of our own expectations of what patients should be, or act like..."¹² Secondly, figures discussing rehabilitation are important, but misleading in many cases because many researchers define rehabilitation as returning to employment. We disagree because many people, though not employed, participate in productive activities.

In order to facilitate rehabilitation to a satisfying level of productive activity, it is necessary to recognize and deal with psychological stresses. It is well documented that there are numerous psychological stresses associated with hemodialysis.⁵⁻⁹⁻¹²⁻¹³ The most dominant home training stress that we found in our survey was anxiety, which resulted from many factors. Among these were insecurity about the future, the awesome and largely unknown responsibility of home dialysis, the need to be dependent on the machine and loved ones, and the ambivalence about being able to learn dialysis. It is an established teaching principle that anxiety levels must be lowered before learning can take place.⁷ Methods used in our program which have proved helpful in decreasing anxiety and facilitating learning, include the following: an orientation day prior to training, encouragement of open communication between staff and learners, both in individual and group sessions, positive reinforcement throughout the course, and individual instruction.

Our program's orientation day allows us to accomplish several goals. We can begin to assess the present status of the patient and the partner. This assessment of the trainee's abilities and emotional needs is necessary before we can plan individual teaching approaches. We also have the opportunity to explain what can be expected from the course and the teachers, as well as what is expected from the learners during the course. We utilize the relaxed atmosphere of orientation to familiarize them with the basics of dialysis such as vital signs and charting. We use the accomplishment of these small tasks to provide them with positive reinforcement of their abilities and to motivate them to accomplish more difficult ones. This positive reinforcement is continued throughout the training process to facilitate and maintain motivation and confidence. It was brought to our attention by the participants in the study that new trainees can receive encouragement from someone who has successfully completed the program. It was suggested that this visit be included in orientation. Several of the patients and partners interviewed enthusiastically offered their time to do this.

After laying the groundwork during orientation, we begin on the first day to encourage open communication and to emphasize the need to ventilate anger and frustration which are common during the training period. Both individual and group sessions are utilized.

Continuous support and patience are vital throughout the course, but they are particularly important during needle insertion and the handling of stressful situations such as blood leaks and needle problems. These were found to be the most frequently mentioned technical stress factors of home dialysis. Our survey revealed that the majority of the sample felt a strong need to experience the complications of dialysis during the course and to have a thorough manual to take home with them. Our program has provided both for the past 3 years. Some of the people who were trained in the early phases of the program complained bitterly about not being taught the "whys" behind the procedures and machinery maintenance. We feel that these areas need to be taught and we emphasize them in our program. If home training is structured, we feel that 4 weeks is an adequate length, but it should be flexible in order to allow trainees to progress at their own speed without pressure. Our survey confirms this.

Even though the approach to training is the single most important factor to successful adjustment to home dialysis, there are still ongoing needs that must be dealt with in order to make home dialysis as pleasant as possible. From our survey it was found that home dialysis became routine after the first 3 to 6 months. Anxiety decreased. Of the 10% who continued to find the responsibility of home dialysis awesome, most remained anxious because of a fear of possible complications. In some, concern was justified because of past complications. For the others, psychotherapy may be indicated. Some partners who were working full time, noted that even though anxiety decreased, the time involved was a burden. Family members, including children, usually did not find dialysis threatening, and that helped in many cases. One of our main reasons for conducting this research was to find ways of making home dialysis more acceptable.

We had an overwhelmingly positive response from the patients and partners regarding the needs for better communication, continuing education, and group sessions. Many felt abandoned and isolated from the staff and physicians after going home. It is interesting to note that those who did not express feelings of isolation and abandonment were those who remained in close telephone contact with the staff and physicians, or who had contact with a member of the home training staff who maintained some of the machinery. We agree with Brown⁴ and Blagg³ that home visits, although time-consuming, help in assessing patients' needs and progress. During the visits, we noted that patients and family were aggressive in asking questions about technical aspects and finances. In most cases they freely discussed emotional and social concerns. By talking to the patients in their own home environment, we were better able to get to know them and to identify their needs. Since the initial visits, we have had frequent calls from patients who before had little contact with our center, the home training staff, or the social worker. We recognize that frequent home visits, particularly those involving long distances, may not always be feasible because of the time and cost involved. We do feel, though, that home visits should be made soon after the patient goes home and at least yearly thereafter. If situations do arise in which first hand observation of the family situation or home environment seems advisable, the staff should be flexible in their scheduling of visits. Between visits, frequent and regular telephone contact should be made. By doing this, problems, if present, may be identified. This also makes the patient aware that he has not been abandoned and that the staff is available. In order to keep our patients abreast of the advances in the treatment of end stage renal disease, and the changes in techniques, we are in the process of organizing continuing education classes. A bi-monthly newsletter already features a column dealing with dialysis related subjects.

It is well known that personal sacrifices such as limited travel, mental and physical exertion, and loss of sleep are required of the partner of the home dialysis patient.⁴ The idea of allowing patients to dialyze in-center for several weeks a year in order to give the partners a vacation from the responsibilities of dialysis, was received with enthusiasm by our sample. Because of this, we have adopted a vacation plan into our program and encourage patients to utilize the

opportunity. We also encourage patients to travel and we make the necessary arrangements for transient dialysis. Important to the successful adjustment of families to home dialysis, is the need for planned psychological support in the form of individual and group sessions. Our survey revealed a strong support for this, particularly in the early period of home dialysis.

CONCLUSION

The dialysis population across the United States is increasing. In-center dialysis beds are being filled at a rapid rate. Training patients for home dialysis leaves beds free for those who are medically or psychologically unstable, lack a suitable partner, or lack an environment suitable for dialysis. Because of this, home dialysis may, in the future, again be a necessary and unavoidable mode of treatment for end stage renal disease. Our study has shown home dialysis to be both feasible and desirable. The key to successful home dialysis is through training and preparation, emotional and medical support, and careful follow-up by physicians and training staffs. If these needs are met, then indeed, home dialysis can continue to be an acceptable mode of treatment for end stage renal disease.

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