Psychological aspects of home care for the patient with end-stage renal disease[1]

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Increased utilization of home therapy for end-stage renal disease has a profound effect on patients and their families. Common psychological problems faced by patients on home hemodialysis are reviewed and specific problems associated with continuous ambulatory peritoneal dialysis (CAPD) are discussed, such as marital discord, body image, and depression. Illustrative cases are presented and treatment suggestions are offered.

Index term: Home care services

Cleve Clin Q 52:299–302, Fall 1985

The rapid advance of technology from the research laboratory to the intensive care unit, the regular hospital nursing unit, and finally into the home, has been an exponential growth phenomenon. Unfortunately, in the course of this process, adequate attention has not always been paid to the personal and interpersonal needs of the patient and his or her family. While the technical aspects of home care are fairly similar irrespective of the specific support system, i.e., dialysis, parenteral nutrition, or mechanical ventilation, the patients and their families are not, overriding any similarity of technology or disease. The reductionistic approach of referring to "Crohn's patients" or "dialysis patients" is inadequate for meeting the needs of *persons* who happen to have disease. The purpose of this paper is to discuss the specific psychological issues involved with home dialysis.

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0009-8787/85/03/0299/04/$2.00/0

Home dialysis

Home hemodialysis

Although early results of chronic in-center hemodialysis were encouraging, it soon became apparent that the cost was prohibitive even on an outpatient basis.[1] This led to the concept of home hemodialysis, which was first used in Boston in 1963, in Seattle and London in 1964, and at the Cleveland Clinic in 1966.[1] Several authors have demonstrated that specific physical, psychological, and stress factors are associated with an increased probability of failure when a patient enters home dialysis. In 1972, Blagg noted moderate or severe psychological problems in 35% of his hemodialysis patients.[2] In 1975, Popowniak et al found a 56% prevalence of psychological problems which were considered highly significant in 8 of the 9 patients whose treatment was unsuccessful.[1] In 1979, Lowry reported depressive disorders in 22% of patients entering home hemodialysis,[3] while Farmer et al described a 31% incidence of psychological illness in a similar group. They attributed failed home hemodialysis to psychiatric illness, physical symptoms, absence of full-time employment, and a spouse who could not cope with the illness.[4] Indeed, although Popowniak et al and Blagg found that motivation and the determination to succeed on the part of the patient are the keys to success in a home hemodialysis program, the role of the spouse cannot be overlooked. The husband or wife share many stresses with the patient, i.e., the possibility of death, enormous medical expenses, lost personal opportunities for work, recreation, and travel, and changes in the marital relationship.[5] Shambaugh et al noted in 1967 that the spouse tended to react to hemodialysis with feelings of deprivation and hostility.[6] Holcomb and Macdonald surveyed 23 patients on home dialysis and reported that in 17 cases (75%), the spouse complained of extreme depression.[7] Lowry and Atcherson, in their study of 82 couples on home hemodialysis, reported that 34% of spouses became angry easily, often after six months to the point of shouting and arguing.[5] Home dialysis does have several advantages: the patient has more control over his or her life and treatment schedule, and he or she can perform the dialysis in the comfort of the home without traveling to a medical center and can spend more time with family and at work. Nevertheless, successful home hemodialysis is dependent on a team effort by the patient, family physicians, and dialysis staff.

Continuous ambulatory peritoneal dialysis (CAPD)

When hemodialysis or peritoneal dialysis is used to treat chronic renal failure, psychological stress can develop such as increased dependence on the dialysis machine and renal team, loss of ability to gratify biological or psychological drives, restricted social life, changes in occupation or plans, and loss of autonomy.[8,9] CAPD is now available to patients suffering from end-stage renal disease; though time-consuming and tedious for the patient, it offers the prospect of greater independence and enables the patient to take an active role in his or her own treatment. Since the fall of 1979, more than 100 patients have been trained in CAPD at the Cleveland Clinic and currently there are 55 patients in the CAPD program. Prior to starting CAPD, several psychological factors need to be carefully assessed[10]: these include mood and ability to test reality, cognitive function, body image, ability to handle crises, tolerance for environmental stress, personality structure, and both support for and acceptance of treatment by relatives. Although the patient must assume primary responsibility for handling treatment, a spouse or reliable relative should be available in case of a crisis. Possible discord or conflict that could affect motivation or performance is also assessed. Psychiatric contraindications to CAPD include severe depression and psychosis, as such patients lack the motivation to perform exchanges carefully on a daily basis and run the risk of peritonitis or other medical complications. Although most of the patients seen at the Cleveland Clinic appear to adjust to CAPD, a number of psychological problems have been seen, as illustrated by the following case reports.

Case reports

Marital discord. The major incidence of marital discord has involved diabetic patients. Five couples so far have undergone a severe strain in their marital relationship, especially after the patient suffered either blindness or loss of his or her limbs. With progressive loss of body function by the patient, the healthy spouse generally ended up feeling overwhelmed and angry, unable to attend to work and household duties and do the exchanges too, as illustrated by the following case:

Case 1. A 34-year-old married man, the father of two teenage girls, had been diabetic since the age of 12, but described a "good and solid" marriage and a close family.

Over the years, he had experienced considerable loss of vision secondary to diabetic retinopathy (left eye = 20/70, right eye = 20/400); however, the CAPD instructor developed specific techniques that the patient could master, permitting him to perform fluid exchanges with some help from his wife. At this point, his wife took on more responsibility and tried to do everything from looking after the family and household to attending nursing school. She felt overwhelmed and he experienced reactive depression fed by inability to continue his previous independent life style. Referral for marital therapy led to a useful discussion of issues such as dependence versus independence, control, and feelings associated with dealing with chronic illness. He was able to function on CAPD for a year until peritonitis developed and led to death from general septicemia.

Body image. Special attention should be given to the patient's attitudes toward the dialysis bag, the noises produced by the fluids, and the sensation of feeling too full following the fluid exchanges. Sexual problems may arise from the patient thinking the bag is ugly and undesirable. The following patient at first seemed ready for CAPD but proved to be unsuitable because of her underlying attitudes.

Case 2. A 46-year-old mother of two daughters, who had been diabetic for 21 years, asked to change from intermittent peritoneal dialysis (IPD) to CAPD in order to become more independent. She was successfully trained for the procedure but discontinued it a month later because "the fluid made me uncomfortable and I looked pregnant." Further questioning revealed that her "pregnant" appearance reminded her of her stillborn son, a trauma she had not fully come to terms with. She subsequently returned to IPD.

"Burn-out" and depression. "Burn-out" has been encountered more and more frequently, especially in patients who have been on CAPD for a year or longer. Some patients, who were initially highly motivated to take control of their dialysis and performed exchanges four times a day, seven days a week, began to feel "tied down" after a year or so and desired a break from the endless routine. In severe cases, the patient has been switched to either hemodialysis or IPD for a short period. More recently, continuous cyclic peritoneal dialysis has been employed in which the patient undergoes dialysis on the cycler all night and has the entire day free. The following is a case in point.

Case 3. A 42-year-old, obsessive-compulsive man, who had undergone amputation of both lower limbs, had started CAPD about 18 months previously. For the next six months, he felt much better physically, enjoyed doing the exchanges, and particularly appreciated being able to control his daily routine and dialysis schedule. He lived in the basement of his sister's house and took care of his own needs. Six months later, however, he began to feel "tied down" to the dialysis routine; he felt frustrated and did not like becoming more and more dependent on his family. He had to push himself to perform his exchanges, and after a while began to wonder if it was worth it, even considering stopping the treatment altogether. On consultation, it was noted that in addition to "burning out" from the procedure itself, he also had signs of major depression. He was treated with gradually increasing doses of maprotiline, up to 150 mg a day. Four weeks later, he was a different person, his enthusiasm returned, and he continued CAPD. A year later, he again began experiencing signs of "burn-out" and had to be hospitalized briefly to give him and his family a break. With support from the team and his family, he is presently functioning on CAPD.

Discussion

Recent changes in the health care field have persuaded more and more patients suffering from end stage renal disease to perform dialysis in the comfort of their homes. Although most patients and families make a smooth transition, home dialysis is not without problems. Issues of control, dependence versus independence, and anger arising from chronic illness can interfere with treatment. If these conflicts are not addressed adequately, increased family hostility may occur—perhaps resulting in marital discord—and non-compliance with the treatment regimen may be seen. Depression and "burn-out" may be complicating factors. The treating physician and team should constantly be on the lookout for such behavior. Early referral to a psychiatrist or psychologist in certain cases could prevent or arrest some of these difficulties. In order to improve the well-being of patients on home dialysis, then, it is not sufficient to consider only the "dialysis machine," but more importantly, the psychological needs of the patient attached to it.

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References

1. Popowniak KL, Nakamoto S, Magnusson MO. Home dialysis. Eight years' experience. Cleve Clin Q 1975 **42**:225–236.
2. Blagg CR. Home hemodialysis. Am J Med Sci 1972; **264**:168–182.
3. Lowry MR. Frequency of depressive disorder in patients

entering home hemodialysis. J Nerv Ment Dis 1979; **167**:199–204.
4. Farmer CJ, Bewick M, Parsons V, Snowden SA. Survival on home haemodialysis: its relationship with physical symptomatology, psychosocial background and psychiatric morbidity. Psychol Med 1979; **9**:515–523.
5. Lowry MR, Atcherson E. Spouse-assistants' adjustment to home hemodialysis. J Chronic Dis 1984; **37**:293–300.
6. Shambaugh PW, Hampers CL, Bailey GL, Snyder D, Merrill JP. Hemodialysis in the home—emotional impact on the spouse. Trans Am Soc Artif Intern Organs 1967; **13**:41–45.
7. Holcomb JL, Macdonald RW. Social functioning of artificial kidney patients. Soc Sci Med 1973; **7**:109–119.
8. Wright RG, Sand P, Livingston G. Psychological stress during hemodialysis for chronic renal failure. Ann Intern Med 1966; **64**:611–621.
9. Rabinowitz S, van der Spuy HIJ. Selection criteria for dialysis and renal transplant. Am J Psychiatry 1978; **135**:861–863.
10. Gonsalves-Ebrahim L, Gulledge AD, Miga S. Continuous ambulatory peritoneal dialysis: psychological factors. Psychosomatics 1982; **23**:944–949.