

# Problems in Social Adjustment to Hemodialysis

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The person who finds he has been diagnosed as having chronic renal failure is faced with a myriad of adjustments — literally changing his entire life style. Initially the dialysis patient finds himself in a unique and terrifying situation. He has been ill, and now finds his life is maintained by a machine which has taken over a vital organ function. The adjustment of the patient to his new condition will determine whether he lives or dies. Therefore, his management requires a careful look at his situation in his social environment and making the necessary changes to enable his rehabilitation.

Adjustment to chronic hemodialysis falls into three definable categories: 1) emotional, 2) socio-economical and 3) his family or the significant others in his life. Obviously none of these categories is mutually exclusive as each runs into the other in varying degrees. The emotional adjustment of a patient will probably best determine how the other two categories will be managed.

Chronic illness such as this makes demands that may be intolerable for a period of time for even the most stable personality. The speed of adjustment to a radically altered life situation will depend on the maturity of the person and the degree of strength in the family group. (Macnamara, 1967, pp. 1232.).

Levy has discussed the initial emotional stage that a patient goes through as the “honeymoon” period (1973, p. 18). His improved physical condition makes him think he is on the road to recovery.

Immediate reaction appears to be gratitude to the team and to the technique which has allowed a rapid improvement in health. The main problems in adaptation only develop when the patient realizes that he must have dialysis again. (Cramond, 1967, pp. 1203).

Here is where the “honeymoon” abruptly stops and the patient must accept that dialysis will be a permanent life maintenance unless he receives a transplant. His response to this crisis is usually with shock, disbelief and denial. A patient’s denial is an understandable response — an attempt to use time as a buffer between the reality of his illness and any action that he is required to take. Often the patient’s denial makes it necessary to repeat his condition to him, that it is chronic and not acute and even his dialysis appointments, instructions for care of his A-V shunt etc. must be repeated, (Ibid.) One new dialysis patient who came into our unit had particular problems in getting her appointments right or in taking care of her new shunt. She

This paper is written by the students of the Dialysis Instructors Training Program — University of Utah Medical Center, Home Dialysis Training Center — as part of their requirement.

would blame the staff for not informing her of when she was scheduled for dialysis and in spite of repeated cautions about checking her shunt, eventually had a problem with clotting which wasn't noticed until her next appointment. The patient's denial of his condition makes him reluctant to acknowledge any dialysis-related instructions or information (e.g. "Do you remember which is the arterial side of your shunt?" "No."). Acceptance of, or discussion about dialysis is a tacit acceptance of his condition which he is not yet prepared to face.

Following a period of denial the patient may go through a long depression. Levy describes this as a period of "disenchantment and discouragement." While the patient is obviously sad and feels a sense of hopelessness it is nevertheless a significant sign that the patient has come to accept the permanence of his illness. "Long term adjustment" (Ibid.) can follow only after this realization. Now the adjustment moves into how he can relate to his treatment, the conflicts he feels about his new dependency upon a machine and his self-image. Often he will depend upon the staff to take care of his dialysis, taking little interest in it himself. Sometimes this is the way he will express his anger at others around him or his frustration with his illness. A patient in our unit declared that she would not take anymore of her medication until the doctor looked at her rash which turned out to be rickets. Stopping her medication was her way of expressing her anger because she believed that she was being neglected. Skipping medications and neglecting diet are common ways a patient expresses anger to the dialysis staff. A young patient who has had some particularly difficult socio-economic problems since on dialysis came into the unit grossly fluid overloaded one day and announced that he had drunk a gallon of milk the previous day. It turns out that he had had a serious financial upset; abusing his diet was his means of expressing his frustrations. These examples are given to make a point: when a patient does something which appears to be foolish or dangerous to himself, he is probably trying to tell us something.

Dependency feelings are enhanced by anxiety over a clotted A-V shunt or availability of blood access sites. Cramond (1967, p. 1206) mentions anxiety symptoms over such things as Cushing's Syndrome, oliguria and skin pigmentation. Another common anxiety is a fear of mechanical failure on the machine. Patients who are dependent upon staff members for their physical well-being are very sensitive to staff changes (Macnamara, 1967, p. 1232). They develop favorites and may become angry if the people whom they depend upon specifically aren't available to them. This has been manifested many times in the unit in which I work, with patients who allow only certain people to insert catheters in their arms and become upset if their wishes aren't met.

In the broader outlook, the dialysis patient must make tremendous changes in his life style. Here again his self-image is threatened as he is forced to change roles. Often a male patient's wife finds it necessary to go to work to support the family or a woman may find that her time spent on dialysis makes it impossible for her to be a full-time mother to her children. Such role reversals or changes make great demands on a person's feelings of self-worth within the family unit. Economic concerns for the family stability and the patients medical costs may require drastic changes in such things as living accommodations, transportation expenses to and from the dialysis unit and child care expenses. Dialysis patients may find it necessary to change jobs in consideration of their physical well-being as well.

In addition to changes in economic structure within the family, there is also the consideration of the patient's new diet and how it will be handled. The family will be required to make certain dietary changes unless the patient is to have a completely separate menu. If the patient does not do his own cooking, another family member must be concerned for his diet restrictions when cooking and planning menus. The patient wants to be normal and maintain as normal a life style as he can with his family members. A great strain is put on the family to make a smooth transition to accommodate the patients needs and still maintain themselves as normal healthy individuals, separate from the patient. How well the patient's family can effect these transitions and be supportive will be very significant in the patients adjustment to his dialysis (Odem, 1973, p. 63.).

The above discussion of adjustment problems illustrates how interconnected the emotional, economic and familial adjustments are. However, the first step must be towards giving the emotional stability the patient needs. With his own self-worth and self-concept restored, he will be better capable of solving his economic dilemma and continuing a vital relationship with his family.

One of the most important considerations in the patient's adjustments is providing a healthy communication outlet for him. The patient needs the understanding of the dialysis staff including a social worker to whom he can turn to express his fears and frustrations as well as to vent his anger. Anger is a phase in adjustment as predictable as denial. The dialysis staff should try to understand it as an emotional communication and a stepping-stone to accepting his illness. Strict therapeutic regime deprives the patient of outlets for his tensions (Cramond, 1967, p. 1208). The need to "get along" with the dialysis community may prevent a patient from expressing himself and what makes him angry. Anger and depression are not exclusive to the patient. Family members have many conflicting feelings concerning their ill family member. Many times the ill or dying patient will cause the family to withdraw from him, being unable to handle the feelings of anger and depression due to the threat of losing a loved one. If the family cannot cope with these feelings, if they cannot be expressed to a social worker or an understanding party, they have no outlet. Kubler-Ross has emphasized the importance of the family being able to express themselves, to be honest with their feelings and to ultimately be able to maintain a vital relationship with the patient because of their own insight. The social worker can act as a liaison between the family and the patient to ensure that communications do not break down and also as a liaison between the patient and the community to which he wants to return. When the family is capable of assuming a supportive role to the patient they can supply the patient with a feeling of self-worth and the assurance that he is still a viable member of the family. In conjunction with the family the social worker can redirect the goals of the patient to accommodate his new life style, encouraging him to extend himself to all of his capabilities. "It is important for members of the team to consider carefully how much the patient can do for himself since this leads to a change of self image, reflecting more positive aspects of the personality" (Cramond, 1967, p. 1235).

Perry (1974, p. 25) synthesizes how the dialysis staff can best meet the patient's needs in the following recommendations: 1) Promote self esteem - by allowing, even demanding, that the patient participate in the decision-making regarding his life. 2) Identify to the patient the realities of his disease and treatment, making certain he is

aware of the recourse of his actions, e.g. if you drink in excess of your 1,000 cc/day, your kidneys cannot handle it, your body will retain it, your ankles may swell, you may have difficulty breathing and heart failure. 3) Offer him free choices whenever possible, without threat of recrimination, e.g., establishing his own medication schedule, meal selection, etc. 4) Encourage him to verbalize his fears and give knowledgeable personal responses to him; knowing that structured responses to a personal problem bring only frustration. 5) Assist him in setting realistic goals for himself and 6) give him hope.

In summary, the following points should be remembered. The patient in his adjustment to dialysis will go through observable phases towards coming to terms with his chronic illness, unless he stays in one phase (denial, for example) without being encouraged to progress beyond it. Of the three major areas of adjustment, emotional, economical and familial, the emotional adjustment will best facilitate coming to terms with the other two. Keeping an open, smooth communication with the patient, giving him adequate opportunity to express his feelings and being a perceptive listener are the best supportive qualities the dialysis staff can have. Encouraging a patient to care for himself, take an active part in his treatment and his diet will help to enhance the patient's self-image and restore his feelings of independence. The patient's family can be most valuable as a support for the patient during his initial crisis if they can be helped to understand their own conflicting feelings. The social worker can maintain the viability of the family unit by helping to solve the daily events which need attention. In short, the staff should be available for more than the technical procedure of the patient's treatment and should play an active role in helping a new dialysis patient come to terms with the psycho-social problems of dialysis.

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