

COMMON PSYCHOLOGICAL FACTORS IN THE TREATMENT OF END STAGE RENAL DISEASE

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How can we understand the trauma of a person with end stage renal disease (ESRD) and its impact on his or her life? Is there a relationship between the patient's thoughts and feelings about his or her illness, and their compliance or non-compliance with treatment? Social workers are uniquely qualified to help patients and their families with the psychological consequences of ESRD.

Key Words: ESRD, compliance, social work, end stage renal disease, transplantation.

Although the literature on the treatment of end stage renal disease is growing, more needs to be written about the psychological aspects of the illness. Physicians and nurses share a technical focus and sometimes do not relate to the person with ESRD as a unique individual. Nevertheless, chronic illness is frequently associated with depression, fear and other distressing feelings. Fatigue, weakness, nausea, physical limitations, loss of functioning, changes in bodily appearance and the cumulative impact of struggling with a life-threatening illness will inevitably affect the patient's feelings.

ESRD affects the patient in many ways. It is the cause of major modifications in lifestyle, life goals, vocational choices, opportunities, recreational activities, interpersonal relationships and family role or position. However, most of the patients whom I informally interviewed at conferences and in health care settings reported that during the course of their illness, health care providers routinely failed to inquire about the patient's emotional state. One patient who had kidney failure due to lupus complained that on the first day she was dialyzed, the patient next to her died, and that even then, none of the staff asked her about feelings and concerns. Social workers' roles are often reduced to the provision of concrete services, but we are uniquely qualified to assist the ESRD patient and the patient's family with the psychological aspects of the disease. Social work training and values promote the importance of understanding the whole person within his environment. Social workers have been taught to view each person according to his culture, religious beliefs, educational level and developmental level. Whether the patient's illness is newly diagnosed or the patient has been ill for a long time will impact the patient's emotional state in different ways. Renal professionals are well aware of the importance of educating the patient about diet and medication. Numerous articles and workshops address the problem of patient non-compliance (Gray, 1998). Unfortunately, even patients who have been thoroughly advised about their health needs have difficulty following their health care team's recommendations. In these numerous cases, when non-compliance is not due to ignorance, it is usually due to psychological factors. (There are also cases where the problem of non-compliance is due to financial inability to purchase medicine or attend doctor's appointments; however, this is not the focus of this article. Even in cases of financial hardship, emotions like shame and depression may disguise the monetary reasons for the non-compliance.) Therefore, the social worker performs an important role by openly listening to the patient and allowing him or her to express his or her feelings during the psychosocial assessment (Hirsch, 1992). If the patient is struggling with negative emotions, the social worker can identify these issues and explain that psychotherapy can help the patient to cope with these difficulties. The social

worker who has too large a caseload can offer a referral to an appropriate clinician or provide treatment directly.

The patient with ESRD is confronted with many difficult issues and feelings.

Fear. The patient is afraid for many different reasons. There is fear of the unknown, fear of surgery, of loss of body parts, of loss of functioning; fear of falling apart, of loss of job, of loss of income and loss of love; fear of pain, disfigurement, of suffering and of death. There are often fears related to the family such as what will happen to their children or spouse if they become disabled or die.

Trapped. Living with chronic, deteriorating illness has been likened to becoming a prisoner in a concentration camp where one is subject to uncontrollable, unpredictable and evil forces (Lipsyte, 1998).

Anger. Anger has many sources. Patients may be angry about getting ESRD and want to know what they did to deserve the illness. They may alternate between blaming themselves, blaming God, blaming fate and blaming the entire world. The medical team may be blamed since they informed them of their kidney failure but failed to cure the disease. Often what seems to infuriate patients the most is when their health care providers view them as just cases and do not seem interested in them. Whether it is true or untrue that professionals do not care much about patients, the angry patient may arouse counter-resistance in the medical team, only compounding the patient's problems (Simmons, 1987).

Guilt. Patients often feel guilty when they feel they are a burden to other people. One patient refused treatment because he felt he didn't deserve to be helped. Another patient refused to accept her daughter's offer to donate a kidney because she felt her illness had already caused her daughter much deprivation. There may also be guilty feelings due to being so angry.

Hurt. Patients may tend to feel hurt when family, friends or co-workers do not show enough concern about their problems. Whether it is true or untrue that the patient is not given enough attention or consideration about his illness, the patient's perception of being ignored tends to lead to anger, withdrawal and depression.

Shame. Patients may feel ashamed of their illness, especially if premorbidly they overvalued their independence or strength. They may have unrealistically high expectations of themselves and judge themselves too harshly for abilities they have lost. One patient berated herself constantly for being physically weakened since she was unable to work and perform her usual household responsibilities.

Depression. Patients' grief and sadness over their disease may make it difficult to regulate their mood. Loss of hope and expectations of further progression of symptoms may make it difficult for the patient to feel joy and pleasure in activities which they previously enjoyed. They may lose their sense of humor. They may have difficulty sleeping, either waking up constantly or wanting to sleep all the time. They may lose their appetite and lose weight. Depressed people may have difficulty concentrating and making decisions. They may isolate themselves from family and friends. They may have suicidal impulses or suicidal behavior. The depressed patient may feel too depressed to follow a diet, take medication as prescribed or keep appointments. The depressed person tends to think, "Why bother? Nothing can help me."

Medical Management. When the patient is taking medication it is difficult to distinguish symptoms that are caused by the illness from symptoms that may be side effects of the medications. The patient may fail to report significant changes to the health care team. One patient who had acute chest pain still went to work because he feared being fired by his boss for missing too many days. The same patient was reluctant to call his doctor when he was experiencing vomiting because he didn't want to appear to be like a baby.

Relationship to Caregivers. Patients may rely on one or more caregivers to assist with activities that they previously handled by themselves. They may resent their dependency and loss of autonomy and displace their anger onto those who try to help. Unfortunately, this may cause caregivers to withdraw from or argue with the patient. Caregivers often have their own difficulties to struggle with, like worry, exhaustion, fear and loss.

Denial. Every ego defense mechanism, including denial, serves a purpose. People tend to use denial when it is too unpleasant to face reality. Patients may deny an aspect of their illness, deny their feelings about the illness or deny the implications of the illness. They may then minimize problems or seem to be indifferent. This may be the only way the patient has to cope with overwhelming thoughts and feelings. Unfortunately, excessive use of denial as a defense mechanism may cause the patient to fail to obtain necessary treatment. Denial tends to interfere with judgement and problem solving.

Loss. Patients with ESRD experience many losses. They may have loss of bodily integrity, trust, abilities, employment, income, status, role, identity and sexual functioning. Loss of control may lead to rebellion.

Isolation. Patients may isolate themselves due to depression, shame or self-blame. They may also isolate themselves in order to protect others from their pain.

Conclusion

The patient with ESRD struggles with both the physical aspects of the illness and its emotional consequences. The disease also has a tremendous impact on the patient's family. The social worker, by conducting a sensitive and in-depth psychosocial assessment of the patient, takes an important first step in helping him or her to identify his or her major difficulties and supports. Psychotherapy should be considered as a useful method to help patients and families to understand and resolve psychological and interpersonal conflicts which interfere with adherence to treatment.

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