

## **Title Page**

### **Quality of life, Spouse Marital adjustment and Depression in a sample of End-Stage Renal Disease (ESRD) patients in Greece**

Biris A<sup>1</sup>, Messinis L<sup>2</sup>, Antoniadis G<sup>2</sup>, Skarli V<sup>1</sup>

<sup>1</sup>General Hospital of Larissa, Greece

<sup>2</sup>TEI Patras, School of Health Sciences, Department of Speech Therapy, Patras, Greece

#### **Corresponding Authors:**

Argyris Biris, M.Sc.

General Hospital of Larissa

Kondyli 3-5, 412 23

Larissa, Greece

E- Mail: [argyb@hotmail.com](mailto:argyb@hotmail.com)

Tel: ++ 30 410 286 884

Lambros Messinis, Ph.D

TEI Patras, School of Health Sciences,

Department of Speech Therapy

Parodos Nausikas 52, 264 42

Patras, Greece

E-Mail: [lambros@hellasnet.gr](mailto:lambros@hellasnet.gr)

Tel: ++30 610 455 209

## **Abstract**

The present study investigated parameters of the quality of life, depressive symptomatology, and spouse marital adjustment in a sample of ESRD patients in Greece. A self-report questionnaire developed specifically for this study was completed by the patients and a short form of the same questionnaire was developed for completion by the spouses of ESRD patients. Both groups were assessed with the Beck Depression Inventory (BDI) and further clinically evaluated to establish whether they presented symptoms for compliance with the DSM-IV criteria for major depressive disorder and dysthymia. Results indicated high depression rates among ESRD patients and spouses. Spouse marital adjustment was influenced particularly by the duration of the illness, social provision, and financial state of the family as well as coping self-efficacy of the spouse. The above findings, although preliminary, may provide renal unit staff with appropriate psychosocial information about ESRD patients, in an effort to better understand their life style, mood states, and psychosocial needs.

**Keywords:** Quality of life, Depression, Spouse Marital Adjustment, End-Stage Renal Disease, Hemodialysis

## Introduction

The onset of End Stage Renal Disease (ESRD) is defined by an irreversible, total or near-total cessation of kidney function. ESRD afflicts individuals of all ages, ethnic groups, and socio-economic strata. The disorder is slightly more common among males, and is substantially more prevalent among African Americans<sup>1</sup>. ESRD is most commonly due to the advanced complications of another medical condition (e.g. diabetes, hypertension). For other patients the underlying etiology is specific to the renal system (e.g. glomerulonephritis and polycystic kidney disease). Diabetic nephropathy is the most common etiological factor accounting for over one-third of new ESRD cases<sup>1</sup>.

Only three decades ago, a diagnosis of ESRD meant near-certain death. Upon the cessation of renal function, excess fluid, metabolic toxins, and electrolytes rapidly accumulate in blood and bodily tissues. These substances must be removed by alternative means if the ESRD patient is to survive. Current renal replacement therapies include renal transplantation and several forms of renal dialysis. Renal grafts come from either a cadaveric (brain dead) or living (typically a first-degree relative) donor. Despite recent advances in immunosuppressive therapy, activation of the patient's immune system, resulting in organ rejection and failure, remains an important limitation to the potential benefit of transplantation. The success rate for cadaveric donor is lowest, with a five-year graft survival rate of approximately 53%. For organs from living related donors, a five-year graft survival rate of 70% has recently been reported<sup>1</sup>. Despite the superior success rate for living related donation, a large majority (approximately 75% of renal transplants actually performed, involve cadaveric donors<sup>1</sup>.

Given a shortage of donor organs and a significant transplant rejection rate, most ESRD patients rely on some form of renal dialysis as treatment for the condition. Currently, approximately 75% of the ESRD patients are being treated with one of two forms of renal dialysis<sup>1</sup>. These primary dialysis modalities are center hemodialysis (approximately 82% of dialysis patients) and continuous ambulatory peritoneal dialysis (CAPD) (approximately 13% of dialysis patients).

There is an important difference in the role taken by the patient while undergoing the different forms of dialysis. The center hemodialysis patient is a passive recipient of treatment in the confines of a dialysis center/unit. Hemodialysis achieves removal of toxins and excess fluid via the circulation of blood through an artificial kidney (the dialyzer). The dialysis procedure is performed three times a week by trained technicians in a hospital setting, requiring approximately four hours per session. Hemodialysis treatment commences by way of a vascular connection made between the dialysis machine and the patient, usually through an arteriovenous fistula permanently placed in the patient's forearm. Little participation is allowed or required of the patient while undergoing the procedure. During hemodialysis, patients may experience a number of psychological stressors including rapid drops in blood pressure, excess bleeding at the access site, nausea, muscle cramps, and increased fatigue. For a small minority of patients hemodialysis is carried out at home with assistance from a technician or caregiver. Although mechanically similar procedures are involved, home hemodialysis patients typically have the opportunity to be more actively involved in treatment delivery.

As with most chronic illnesses, patient's nonadherence to the prescribed treatment regimen is a pervasive problem among individuals receiving chronic renal replacement intervention. Adherence to a multifaceted treatment regimen is required of both renal dialysis and transplantation patients. However, the vast majority of adherence studies have focused on

individuals receiving some form of dialysis to compensate for a life-threatening loss of kidney function.

### *Quality of life for ESRD patients*

Quality of life can vary for ESRD patients<sup>2, 3</sup>. ESRD and its treatment cause major alterations in the life-style of most patients, who may encounter frustration in all areas of life including dietary and fluid intake restrictions. As a considerable proportion of the social lives of humans revolves around eating and drinking, restricted social participation is almost inevitable for these patients. Another alteration of life-style includes the probable loss of financial security, resulting from lower productivity and income, and possible unemployment. Commonly, there is also role reversal, with the assumption of added responsibilities by the spouse or partner, resulting in a loss of authority for the patient<sup>2, 4</sup>. According to reversal theory, people switch modes (roles) and when in one specific mode, their behaviour differs from that of another mode. Role reversal in renal patients can be seen as a mode-switch from independent to dependent partner. Sexual dysfunction and infertility can further contribute to a decreased quality of life and an impoverished life for the patient. In this regard ESRD patients require careful biopsychosocial evaluation, as results of several studies point to marked deterioration in the sexual functioning of patients, especially males, undergoing dialysis. There is however, minimum information available to the exact cause of sexual dysfunction in these patients. Choice of dialysis mode does not appear to necessarily affect coping styles in these patients, although it might reflect some differences in social interaction and psychological adjustment<sup>2</sup>.

The availability of different treatment modalities, each with its own unique characteristics and patient demands, makes the management of ESRD unique. Hemodialysis, CAPD, and renal transplantation are all medically acceptable treatment alternatives for the large majority of ESRD patients. The different treatments have not generally been linked to differences in patient's survival<sup>5</sup>. There is some indication that a successful renal transplant holds certain advantages in terms of patient quality of life (e.g. less emotional distress, greater mobility)<sup>6, 7</sup>. However, there is little evidence of quality of life differences among patients using the various types of renal dialysis<sup>2, 8</sup>. In general, the choice of a particular ESRD treatment modality is largely a function of nonmedical factors, including patients and provider preferences and judgements about which modality would provide a particular patient with the highest quality of life.

### *Patient Depression in End Stage Renal Disease*

Individuals with ESRD face a variety of chronic recurrent stressors, significant lifestyle disruption, and threatened personal control. Thus, it is not surprising that high rates of depressed mood are commonly observed in ESRD patients<sup>9-13</sup>. Estimates of the prevalence of clinical depression in this population have varied substantially depending on differences in the method and criteria used to define a depressive disorder. Craven, et al. (1988)<sup>10</sup> reported that 45% of their ESRD patients sample was identified as depressed using the Beck Depression Inventory (BDI: i.e. BDI score greater than 10), but only 12% were diagnosed with major depressive disorder using more stringent criteria from the Diagnostic and Statistical Manual of Mental Disorders (3<sup>rd</sup> ed., DSM-III). Lowry and Atcherson (1980)<sup>14</sup> reported an even higher rate (18%) of DSM-III - defined major depression among patients who were just beginning treatment. This finding suggests that psychological distress may be greater at the outset of treatment. Other evidence suggests the rate of more chronic, moderate depression (i.e. dysthymia) is particularly high in this population<sup>11, 15</sup>. In general, the available data suggest that 15-30% of ESRD patients meet criteria for a diagnosable mood disorder (either

major depression or dysthymia). This high rate of depression is made even more alarming by epidemiological research reporting the suicide incidence among hemodialysis patients to be 10-100 times greater than the rate in the general population<sup>16,17</sup>.

A factor complicating the diagnosis of depression in this population is the confound between somatic symptoms of depression and physical symptoms of renal failure and side effects of treatment. Typical uremic symptoms seen in ESRD mimic classic somatic symptoms of depression. Like depression, uremia may produce irritability, cognitive deficits, decreased appetite, insomnia, apathy, and fatigue. Other conditions associated with ESRD such as anemia, electrolyte disturbances, and underlying systemic disease (e.g. diabetes) may also mimic depressive symptoms. In addition, ESRD patients may take medications such as anti-hypertensives, corticosteroids, and anti-inflammatory agents, which can produce depressive side effects.

Given the overlap between physical changes associated with ESRD and some symptoms of depression, it is not surprising that nonsomatic or cognitive symptoms of depression appear to more accurately discriminate depressed from nondepressed ESRD patients<sup>11, 13, 15</sup>. For example, Craven et al., (1987)<sup>15</sup> reported that depressed mood, loss of interest, guilt, and concentration problems were significantly associated with a diagnosis of major depression, while only one somatic indicator, appetite and weight changes, were related to major depression in an ESRD sample. The DSM-III-R depression criteria of loss of energy, insomnia, and decreased sexual interest, were common in the entire sample and thus were not useful in distinguishing depressed from nondepressed patients.

## **Methods**

### *Recruitment of participants*

Participants for the present study were recruited from the haemodialysis unit of the General Hospital of Larissa, in Greece. Participation was anonymous in order to avoid compliant answers. The demographical data of our sample is described in Table 1.

### **Procedures**

A self-report questionnaire was developed specifically for the purposes of this study. This questionnaire was composed of items regarding family relationships, work, sexual relationships, use of free time, use of psychotropic medication, and various changes in the way of life of ESRD patients in general, as well as demographical data. A second questionnaire was developed containing specific items, which assessed the psychosocial and interpersonal behavioural effects that the renal dialysis had on the spouses. Participants further completed Beck's Depression Inventory (BDI) and were clinically assessed to establish whether they presented symptoms for compliance with the DSM-IV criteria for major depressive disorder and dysthymia. Where possible, personality assessment devices, such as the Minnesota Multiphasic Personality Inventory (MMPI), and semi-structured interviews were used. The results obtained from these measures are provided below and discussed in an effort to better understand the life style and personality characteristics of dialysis patients and in order to provide aid that is more appropriate from the dialysis unit and the counselling services in a general hospital.

## Results

### *Design and Analysis of results*

A correlational design was utilised. Statistical analysis was provided using parametric tests (students t-test) to compare group means. Intercorrelation matrices were constructed in order to establish relationships between the variables.

Both the semistructured interviews and the questionnaires were quite revealing about many different aspects of the everyday life of dialysis patients. Most patients quit their job. Mean working time for patients before dialysis was 8,19 hours per day (sd=2,89) while after the initiation of the dialysis treatment working time dropped to a mere 0,79 hours daily (sd=1,70). The vast majority depended on state-run pension plans. Many spouses quit their jobs, since then adopting a new supporting role in the family. Fifty-five (55%) reported as the main precipitating factor increased responsibilities.

In the vast majority of patients, the doctor informed the patients about the dialysis procedure. More specifically, 35% of the patients were informed in a doctor's office in the hospital, 24% in the dialysis unit, 27% in the hospital's emergency unit, 8%, in a physician's office, 3% at a private clinic, and 3% of our sample were informed by relatives. The elapsed time between the initial health related problem and the period they were specifically informed that they should be introduced to renal dialysis was 2,8 years (sd=4). This procedure should follow a protocol [for a discussion on this subject see Kimmel (2001)<sup>18</sup>] and while it would appear that there is plenty of time for the patient to be informed, this information is communicated in Emergency Units for a large proportion of these patients.

The use of free time, which was plenty for these patients, had an uneven distribution. They devoted most of their time doing hobbies, travelling (which was however restricted, due to their dependence on the dialysis device), visiting friends (however many reported that problems arose in their interpersonal relations since they started dialysis), and other activities. They spent less free time than before watching television and less time with the family (see also Kaplan de Nour A(1982)<sup>19</sup>). This finding however, will normally depend on the stage of the adaptive process that the ESRD patients experience. It should also be kept in mind that the adaptive process stages, discussed later in this paper, do not necessarily follow the same sequence in all patients.

Fifty-four (54%) of the patients had a BDI score  $\geq 15$ , which in accordance to other studies has a high diagnostic sensitivity and specificity in making the diagnosis of depressive disorder in patients with ESRD<sup>18, 20</sup>. Using a cut-off score of eight, which is clinically acceptable for subjects without chronic illness<sup>18</sup>, such as the spouses in our sample, the prevalence of mild to major depression rate still reached 50%. These findings were further confirmed by using the outlined criteria in the Diagnostic and Statistical Manual IV for depressive disorder. The mean score for both groups (patients' mean BDI score=18,53; spouses mean BDI=14,50), was significantly higher than the average for the general population (patients'  $p < 0,001$  and spouses'  $p < 0,05$ ) and is in accordance with findings from similar studies<sup>21</sup>.

A significant correlation was found between depression and educational level, indicating that the higher the educational level, the lower the BDI score obtained ( $r = -0,345$ ,  $p < 0,05$ ). The higher educational subgroups were provided with more information about their medical condition and consequently had better control, which might explain this finding. Another significant factor was the current financial status of the patient. Specifically, it would appear that the lower the income, the higher the scores on BDI ( $r = -0,326$ ,  $p < 0,05$ ), which is in keeping with other studies relating socio-economic status with depression<sup>22</sup>. This finding would further indicate the need for provision of support to these patients, not only through a

pension funds plan, but by also providing them with the opportunity to be both productive again and, for the lower income groups, increasing their income. In addition, depressive mood between patients and spouses was positively correlated ( $r=0,749$ ,  $p<0,01$ ). This indicates an increased need for the provision of psychological support to spouses along with the patients.

The BDI scores obtained seem to generally agree with the coping models proposed by other studies<sup>23</sup>, i.e. a brief honeymoon phase followed by a period of disenchantment and discouragement followed by, finally, a period of long-term adaptation (see Figure 1). It appears that depression reaches high levels during the first two years after the initiation of dialysis, and then it decreases, reaching the lowest point for patients following approximately ten years of treatment. However, an increase in BDI scores was re-observed for patients being in the unit for 14, 15 or even 16 years. Similar variation was observed for the spouses, but for them, while the initial elevation follows a similar pattern as for the patients', the lowest scores are observed much earlier, during the 5<sup>th</sup> year of dialysis, and they increase again at an earlier period.

### **Figure 1**

On interfamilial relationships, our observations were as follows: Patients reported that relations with the spouse, after they started dialysis, had become worse, as opposed to the expected improvement in interrelational behavior due to the expected increase in spouse support. Both groups agreed on the way they viewed their relationships with their children (mode was that they "remained the same"), the frequency of sexual intercourse, and the sexual desire after they started dialysis (both were generally reduced).

The MMPI did not show clinically significant elevation in any of the basic scales higher than the average of the general population, except for the first three, i.e., (1) hypochondriasis, (2) depression, and (3) hysteria, which make up the so called neurotic triad. This finding was associated, according to other studies<sup>24, 25</sup> with somatization, apathy, dependency, irritability, and self-centeredness. While the elevation in the depression scale agrees with the BDI measurement, a closer investigation on the other scales (1 and 3) shows that many of the patients' answers (such as the one on the inventory item "I do not get tired easily") were affected by their medical condition and could not be attributed solely to psychological characteristics. Therefore, certain considerations should be taken into account for the use of this instrument with this specific group of patients.

No statistically significant psychiatric comorbidity was observed. The use of psychotropic medication was high in our sample. Antidepressants were used to treat 8% of the patients, 16% were treated with sedatives, and 8% with anxiolytics without veiling between the medications. While these proportions appear to be relatively high compared to the general population, any true estimation of the significance of this finding is difficult, since many prescription drugs in Greece are purchased over the counter. (This is especially true for the anxiolytic group and less for the antidepressants.)

### **Discussion and Conclusions**

The present study examined the quality of life, spouse marital adjustment and depression in a sample of ESRD patients in Greece. Results indicated high depression rates among ESRD patients when BDI scores were considered, i.e.  $BDI \geq 15$ , but lower rates when ESRD patients were diagnosed with major depressive disorder using DSM-IV criteria. This rate was higher using DSM-IV criteria for major depressive disorder among ESRD patients who were just beginning treatment. More chronic moderate depression (i.e. dysthymia) was also particularly

high in the sample. Spouse marital adjustment was influenced particularly by the duration of the illness, social provision, and financial state of the family as well as coping self-efficacy of the spouse. Further observations indicated that patients and spouses emphasized the importance of their daily contact with the medical and nursing personnel [see also Kimmel PL (2001) and Levy NB (1984)<sup>18, 23</sup>]; hence, staff in dialysis units should be specially trained not just in terms of medical expertise but also in basic human communication skills.

Since the emotional trauma experienced by patients extends to significant others (i.e. spouses and children), the quality and meaning of life for patients and their nuclear families is significantly affected. Although the dialysis family is subject to stress, spouses frequently see themselves as more satisfied with the family relationship than their healthy counterparts, as they are compelled to a specific closeness to establish a lower conflict climate within the family partnership. The stresses imposed on the marriage, however, frequently result in disruption, despite findings that couples with marital discord often see their marriages as satisfactory. Personal clinical experience (authors) has shown that relationships involving unmarried couples who cohabit are particularly vulnerable in this regard, as such relationships frequently waver when the full reality of the chronicity of the disease and its complications are realized – especially in young couples contemplating marriage. Given the issues discussed thus far, the pervasive effect of the disease on family relationships should be clear. Whilst family support is important for satisfactory adjustment, anxious spouses can generate anxiety in dialysands. Apart from the noted role-reversal that commonly occurs, dialysis families have to adjust to a narrower social world, re-organization in household tasks, concern with finances and, in order to diminish stress, to an apparent tacit agreement that stressful or tension – provoking topics are to be avoided in discussion, particularly with the children.

In conclusion, it would be useful in future studies to investigate the possible interaction between psychosocial parameters, such as the ones examined in the present study, and biological indices. Finally, findings in this study, although preliminary, may provide renal unit staff with appropriate psychosocial information about ESRD patients, in an effort to better understand their life style, mood states, and psychosocial needs.

## References

1. US Renal Data System. USRDS Annual Report. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 1995.
2. Schlebush L. Medical psychology and psychonephrology. Contributions of clinical psychology. S Afr J Psychol 1986;16:47-56.
3. Bremmer BA, McCauley CR, Wrona RM, et al. Quality of life in end stage renal disease reexamination. Am J Kidney Dis 1989;13:200-209.
4. Kaplan De-Nour A. An overview of psychological problems in hemodialysis patients. In Levy NB, editor. Psychonephrology. Psychological Problems in Kidney Failure and Their Treatment. New York: Plenum; 1983.
5. Flechner SM. Current statues of renal transplantation: Patients selection, results, immunosuppression. Urology Clinics of North America 1994;21:265-282.
6. Christensen AJ, Holman JM, Turner CW, et al. A prospective examination of quality of life in end-stage renal disease. Clin Transplant 1991;5:40-47.
7. Evans RW, Manninen DL, Garrison LP, et al. The quality of life of patients with end-stage renal disease. N Engl J Med 1985;312:553-559.



8. Simmons RG, Abress L, Anderson C. Rehabilitation after kidney transplantation. In Cerilli GJ Editor. Organ transplantation and replacement. Philadelphia: Lippincott; 1988. p. 481-489.
9. Christensen AJ, Holman JM, Turner CW, Slaughter JR. Quality of life end-stage renal disease: Influence of renal transplanation. Clin Transplant 1989;3:46-53.
10. Craven JL, Rodin GM, Littlefield C. The Beck Depression Inventory as a screening device for major depression in renal dialysis patients. Int J Psychiatry Med 1988;18:365-374.
11. Hinrichsen GA, Lieberman JA, Pollack S, Sternberg H. Depression in hemodialysis patients. Psychosomatics 1989;30:284-289.
12. Rodin G, Voshart K. Depressive symptoms and functional impairment in the medical ill. General Hospital Psychiatry 1987;9:251-258.
13. Smith MD, Hong BA, Robson AM. Diagnosis of depression in patients with end-stage renal disease: Comparative analysis. Am J Med 1985;79:160-166.
14. Lowry MR, Atcherson E. A short- term follow-up of patients with depressive disorder on entry into home dialysis training. J Affective Disorders 1980;2:219-227.
15. Craven JL, Rodin GM, Johnson L, Kennedy SH. The diagnosis of major depression in renal dialysis patients. Psychosomatic Med 1987;49:482-492.
16. Abram HS, Moore GL, Westervelt FB. Suicidal behavior in chronic dialysis patients. Am J Psychiatry 1971;127:1199-1204.
17. Haenel TH, Brunner F, Battegay R. Renal dialysis and suicide: Occurrence in Switzerland and in Europe. Comprehensive Psychiatry 1980;21:140-145.
18. Kimmel PL. Psychosocial factors in dialysis patients. Kidney Int Dis 2001;59:1599-1613.
19. Kaplan De Nour A. Social adjustment of chronic dialysis patients. Am J Psychiatry 1982;139:96-100.
20. Craven JL, Rodin CM, Littlefield C. The Beck Depression Inventory as a screening device for major depression in renal dialysis patients. Int J Psychiatry Med 1988;18: 365-374.
21. Israel M. Depression in dialysis patients: A review of psychological factors. Can J Psychiatry 1986;31:445-451.
22. Joel S, Wieder SM. Factors involved in adaptation to the stress of hemodialysis. Smith College Studies in Social Work 1973;43-3:193-205.
23. Levy NB. Psychological complications of dialysis: Psychonephrology to the rescue. In Fifth Annual Vail Psychiatry Conference: The interface between medicine and psychiatry. Bull of the Menninger Clinic 1984;48:237-250.
24. Pierce DM, Lawton R, Freeman R, Fearing M. Psychological correlates of Chronic hemodialysis estimated by MMPI scores. Psychology 1973;10:53-57.
25. Somer T, Sakac V, Vodopivec S, Radmilovic N, Curic S. Depression and anxiety on chronic hemodialysis treatment. In: Boletis JN, Iatrou Ch, Siakotos M, Stathakis ChP, editors. Proceeding of the 5<sup>th</sup> Congress of the Balkan Cities Association of Nephrology Dialysis, Transplantation and Artificial Organs. 2001; Sept 30-Oct 3; Thessaloniki, Greece. p. 108-109.

**Table 1: Demographical data of the sample**

		<b>Patients <i>n</i> (<i>f</i>)</b>	<b>Spouses <i>n</i> (<i>f</i>)</b>
Sex	Males	23 (62,2)	16 (43,2)
	Females	14 (37,8)	21 (56,8)
Marital status	Married	27 (73,0)	27 (73,0)
	Single	7 (18,9)	10 (27,0)
	Divorced	2 (5,4)	-
	Widow/er	1 (2,7)	-
Education	Illiterates	3 (8,1)	10 (27,0)
	Elementary School	20 (54,1)	20 (54,0)
	Gymnasium (9 yrs complementary education)	6 (16,2)	4 (10,8)
	Lyceum	4 (10,8)	1 (2,7)
	Higher education	4 (10,8)	2 (5,4)
Age groups	-25	3 (5,6)	2 (5,4)
	26-35	9 (16,7)	7 (18,9)
	36-45	11 (20,4)	6 (16,2)
	46-55	14 (25,9)	11 (29,7)
	56-65	10 (18,5)	8 (21,6)
	65+	7 (13,0)	3 (8,1)
Financial status	Good	5 (13,5)	4 (10,8)
	Rather good	4 (10,8)	2 (5,4)
	Average	17 (45,9)	13 (35,1)
	Rather bad	6 (16,2)	9 (24,3)
	Bad	3 (8,1)	8 (21,6)
	Extremely bad	2 (5,4)	1 (2,7)
Living area population	Under 5000	14 (37,8)	19 (51,3)
	Up to 20000	4 (10,8)	3 (8,1)
	More than 20000	19 (51,4)	15 (40,5)

**Figure 1: BDI scores over time in dialysis**

