Being a hemodialysis patient. Is it a disruption in life?

Aydan Akyuz Ozdemir[1], Ebru Hatice Ayvazoglu Soy[2], Rengin Erdal[1]

[1]Baskent University, Faculty of Medicine, Department of Public Health, Ankara, Turkey
[2]Baskent University, Faculty of Medicine, Department of General Surgery, Ankara, Turkey

Abstract

Aim: The restrictions of the renal replacement therapy affect the quality of life of patients diagnosed with End Stage Renal Disease (ESRD). The struggle of surviving with the chronic illness brings the need for social support. Herein, we described the perception of the hemodialysis (HD) patients to define the social support to increase the life quality.

Material and Methods: We included 378 (190 females; 188 males) patients in the study. The patients were attending HD sessions for at least six months. Social relations after ESRD diagnosis were evaluated with a questionnaire. A pilot study of the questionnaire was executed at HD centers of Başkent University. According to the results, the language of the questionnaire is simplified. Data were analyzed by SPSS software version 16.

Results: The mean age was 54±16.5 years. Half them had primary school education (54%), where the majority was women. The effect of the HD treatment on the social life was statistically significant in both male and female patients. The percentage of rise in the expectation from the partner (50%) and failing at the family liabilities (45.7%), were higher in male patients. In both gender, the highest percentage was the rise in the expectation from the relatives (females 63.7%; males 66%). The effect of the HD treatment on social and work life found to be changed according to the level of education. As the level of education increased, the percentage of loneliness and social isolation increased. Among all components of social life the need of the partner support was the highest (43.4%).

Conclusion: ESRD patients have a life full of disruptions starting from the first day of diagnosis. Being dependent to a health facility and living with dietary restrictions make their life more unbearable and bring the need for support by all means

Keywords: End Stage Renal Failure; Hemodialysis; Life Quality.

INTRODUCTION

A chronic illness may disrupt the life quality of patients. Having a limited social life, adherence to treatment force them to have a new kind of lifestyle (1-10). The patients diagnosed with End Stage Renal Disease (ESRD) have to survive with different kinds of problems including the renal replacement therapies like hemodialysis (HD). Even though HD reduces most of the symptoms and prolongs the survey, its restrictions are challenging. Changes in the family life, incapability of sustaining liabilities, and financial loss due to treatment and obligation to shift work hours or quit from work, effect HD patients negatively resulting with deep depression as well as poor quality of life (11-21).

Dependence, sexual dysfunction, restrictions on vacation spots, fluid restriction, reduced capacity of work are main stressors of the HD patients determined by several studies (16,22-27). The consequences of these restrictions vary according to the gender, age and educational level of the patient (28). Most studies showed that women and the unemployed ones have the poorest quality of life among HD patients regardless of the age (29-37).

The restrictions and poor social relations may be one of the crucial factors affecting the quality of life of a HD patient. The struggle of surviving brings the need for social support. Otherwise, this vicious cycle makes the HD patient more depressed and in return has negative effects on the treatment itself. As one of the largest institutions in Turkey, Başkent University department of public health decided to describe the perception of the HD patients in order to define the social support needs which will increase the quality of life of the HD patients.

MATERIAL and METHODS

We included 378 (190 females; 188 males) HD patients

in the study. The patients were attending HD sessions for at least six months. The quality of life of the patients was examined in a former study and found that there is a negative correlation between the duration of the HD treatment and the quality of life (29,31).Social relations of the patients after ESRD diagnosis were evaluated with a questionnaire. All HD patients answered the questionnaire independently during HD treatment. The questions were selected from the literature and adopted according to the patient population. A pilot study of the questionnaire was executed at Ankara, Istanbul and Adana HD centers of Başkent University. According to the results of the pilot study, the language of the questionnaire is simplified. All data were analyzed by using SPSS software version 16.

RESULTS

The mean age of HD patients was 54±16.5 years. Half of the patients had primary school education (54%), where the majority of the primary school graduates were women (Table 1). Most of the patients were not working (77.5 %) (retired 18%, worked once 11.1%, not working 48.4%) and the majority of the non-working patient population was female (Tablo 2).

The effect of the HD treatment on the social life was statistically significant in both male and female patients (Table 3). The percentage of rise in the expectation from the partner (50%) and failing at the family liabilities (45.7%), were higher in male patients. In both gender, the highest percentage was the rise in the expectation from the relatives (females 63.7%; males 66%). The percentages in the experience of partner's abandonment (females 2.1%; males 1.6%) and the obligation of living alone (females 2.1%; males 2.7%) were lower.

HD treatment also affects the work life of the patients.

The ages of the participant patients were clustered into 4 groups. The first group included the ones having education in university (18-24 years). The second group included the young working population (25-45 years). Third group included the mature working population (46-65 years). The last group (consisting >65 years of age) included the senior population. There was a significant the effect of the HD treatment on work life according to age clusters (p<0.05) (Table 4). Also there was a negative correlation between age and the effect of HD treatment (p<0.05, r: -0.141) (Table 3).

The ones who were least affected by the HD treatment on their work life were the first (18-24 years; 70%) and the last group (>65years; 66.7%) (Table 3). The effect of the HD treatment on social and work life found to be changed according to the level of education (Table 5). The treatment's effects on those having only primary school education, never worked, and working groups were none. The university graduates were the ones who had to decrease in the working hours mostly (42.9%). The highest number of the working population of the participant patients also belonged to the University graduate group. HD treatment had negative effect on work life (r= - 0.241).

The education level also had an important role on the social life disturbance of the HD patient. The negative correlation between the social life components and education has a significant value (Table 5). The need for social support from partner, friends, relatives and children increased as the educational level decreased (Table 5). As the level of education increased, the percentage of loneliness and social isolation increased. Among all components of social life the need of the partner support was the highest (43.4%).

Table 1.The distribution of the level of education according to the sex of the patients					
SEX	**LEVEL OF EDUCATION**				**Total (n) %**
	Literate/Primary School (n) %	**Secondary School (n) %**	**High School (n) %**	**University (n) %**	
Female	(123) 60.3	(12) 27.3	(30) 40.5	(25) 44.6	(190) 50.3
Male	(81) 39.7	(32) 72.7	(44) 59.5	(31) 55.4	(188) 49.7
Total	(204) 54.0	(44) 11.6	(74) 19.6	(56) 14.8	(378) 100.0
p= 0.000					

Table 2. Distribution of working status of participated patients according to sexes					
SEX	**WORKING STATUS**				**Total (n) %**
	Working (n) %	**Not working (n) %**	**Worked once (n) %**	**Retired (n) %**	
Female	22.4 (19)	78.7 (144)	16.7 (7)	29.4 (20)	50.3 (190)
Male	77.6 (66)	21.3 (39)	83.3 (35)	70.6 (48)	49.7 (188)
Total	22.5 (85)	48.4 (183)	11.1 (42)	18.0 (68)	100.0 (378)
p= 0.000					

Table 3. The effect of the HD treatment on social life of patients according to sexes

The effect of the HD treatment on social life	Sex		Total (378) (n) %	P Value
	Female (190) (n) %	Male (188) (n) %		
Partner's abandonment	2.1 (4)	1.6 (3)	1.9 (7)	0.00
Fail at the fulfillment of family liabilities	31.6 (60)	45.7 (86)	38.6 (146)	0.00
Disrupted relations with relatives	21.6 (41)	16.0 (30)	18.8 (71)	0.00
Increased expectations from children	28.4 (54)	12.2 (23)	20.477	0.00
Increased expectations from partner	36.8 (70)	50.0 (94)	43.4 (164)	0.03
Increased expectations from friends	28.4 (54)	21.3 (40)	24.9 (94)	0.03
Increased expectations from relatives	63.7 (121)	66.0 (124)	64.8 (245)	0.48
Swap of the social community	16.3 (31)	12.8 (24)	14.6 (55)	0.03
Have to live alone	2.1 (4)	2.7 (5)	2.4 (9)	0.48
Decrease social life	14.7 (28)	9.0 (17)	11.9 (45)	0.48

Table 4. The effect of the HD treatment on social life of patients according to age groups

The effect of the HD treatment on work life	Age				Total (367) (n) %	P Value
	18-24 (30) (n) %	25-45 (86) (n) %	46-65 (137) (n) %	65+ (114) (n) %		
Not working before the diagnosis	70.0 (21)	39.5 (34)	50.4 (69)	66.7 (76)	54.4 (200)	
Retired due to disability	-	2.3 (8)	10.2 (14)	7.0 (8)	6.5 (24)	
Forced to swap occupation	6.7 (2)	5.8 (5)	5.8 (8)	4.4 (5)	5.4 (20)	
Quit job and stay unemployed	10.0 (3)	17.4 (15)	10.2 (14)	5.3 (6)	10.4 (38)	0.002
Decrease in the working hours	10.0 (3)	22.1 (19)	16.1 (22)	14.9 (17)	16.6 (61)	
Continue to work as usual	3.3 (1)	5.8 (5)	4.4 (6)	0.9 (1)	3.0 (11)	
Diagnosed after retirement/ quitting job	-	7.0 (6)	2.9 (4)	0.9 (1)	3.5 (13)	
p Value			0.007			
r Value			-0.141			

Table 5. The effect of the HD treatment according to the level of education

The effect of the HD treatmenton work life	LEVEL OF EDUCATION				Total (378) (n) %
	Literate/ Primary School (204) (n) %	Secondary School (44) (n) %	High School (74) (n) %	University (56) (n) %	
Not working before the diagnosis	63.2 (129)	54.5 (24)	51.4 (38)	25.0 (14)	54.2 (205)
Retired due to disability	2.9 (6)	15.9 (7)	13.5 (10)	3.6 (2)	6.6 (25)
Forced to swap occupation	5.9 (12)	4.5 (2)	2.7 (2)	10.7 (6)	5.8 (22)
Quit job and stay unemployed	10.3 (21)	9.1 (4)	10.8 (8)	8.9 (5)	10.1 (38)
Decrease in the working hours	11.3 (23)	11.4 (5)	16.2 (12)	42.9 (24)	16.9 (64)
Continue to work as usual	2.9 (6)	4.5 (2)	2.7 (2)	5.4 (3)	3.4 (13)
Diagnosed after retirement/ quitting job	3.4 (7)	-	2.7 (2)	3.6 (2)	2.9 (11)
p Value			0.000		
r Value			-0.241		
Partner's abandonment	1.5 (3)	-	-	7.1 (4)	1.9 (7)
Fail at the fulfillment of family liabilities	46.6 (95)	38.6 (17)	27 (20)	25(14)	38.6 (146)
Disrupted relations with relatives	17.2 (35)	22.7 (10)	25.7 (19)	12.5 (7)	18.8 (71)
Increased expectations from children	25 (51)	13.6 (6)	13.5 (10)	17.9 (10)	20.4 (77)
Increased expectations from partner	53.4 (109)	38.6 (17)	24.3 (18)	35.7 (20)	43.4 (164)
Increased expectations from friends	22.1 (45)	36.4 (16)	29.7 (22)	19.6 (11)	24.9 (94)
Increased expectations from relatives	77 (157)	70.5 (31)	48.6 (46)	37.5 (21)	64.8 (245)
Swap of the social community	15.2 (31)	2.3 (1)	18.9 (14)	16.1 (9)	14.6 (55)
Have to live alone	2 (4)	-	1.4 (1)	7.1 (4)	2.4 (9)
Decrease social life	9.8 (20)	-	20.3 (15)	17.9 (10)	11.9 (45)
p Value			0.000		
r Value			-0.218		

DISCUSSION

The life depending to a machine to survive disrupts the social and work life. ESRD patients have a life full of disruptions starting from the first day of diagnosis. Being dependent to a health facility and living with dietary restrictions, make their life more unbearable and bring the need for support by all means (4, 6,-8,10,11,19,20,23,31).

The strength of the effect of HD treatment was found to be changing according to the level of education and sex. As most of the studies determined, women under HD treatment have lower quality of life scores than men. This can be a result of the gender roles and duties of women as well as the biological differences (31). Since the gender roles which are defined by traditions of the related country states women's duties, the highest percentage of the need for support from the families and friends was an expected outcome when the discussed patient population belongs to Turkey. Traditions won't let Turkish women to be sick or ill to fulfill their duties as a mother or a partner. They have to continue their course of life with all disturbances (31).

The non-working percentage of the participated patients during the study was 77.5%. The non-working group was composed different clusters such as retired, never worked and once worked but quitted patients. The disturbance effect of HD treatment to patients work life was analyzed through age and level of education.

The most affected population was the age group of 25-45 years, since they had to decrease their working hours (22.1%) and so had to quit their job and be unemployed. This result was not a surprising since the most active working age of an adult is between the years of 25-45. That can be a fact that this cluster was the most affected age group. There happen to be a negative correlation between the age and the disturbance effect of HD on work life. Since the older age group (>65 years) was composed of nearly half of the total patient population, and most of the patients were retired or unemployed, the negative relation of age and disturbance of work life was an expected outcome.

The level of education plays an important role on the effect of the HD as a disturbance factor of social and work life. The higher educated patients were the less affected population from the HD treatment. As several studies have shown, the educational level has a direct relation between the compliance to the treatment and coping with the chronic diseases (38.39). The patients with higher education have high compliance rates and quality of life scores compared to the ones who only had primary or secondary educational level. Since the compliance rates were high, the coping capacities of those patients were more successful which leads to a decrease of the disturbance effects of HD treatment. Besides work life, higher educated patients have the least restriction on their social life due to HD treatment. The results have shown that the higher educated people were more independent than others with fewer expectations from family, relatives and friends. This result may indicate the fact that higher educated people have improved ways of coping with the chronic illnesses

CONCLUSION

Coping strategies can prevent disturbance levels of HD treatment on both social and work life. The negative correlation between the level of education and the disturbance rate is the main factor supporting the importance of education. A training program for ESRD patients can be designed and implemented in order to loosen the effect of the HD treatment on their life. Even though the training programs may help the patients' coping mechanisms, the negative correlation between the need for support and the expectations from family and friends showed the importance of higher education for an independent survival process.

Aydan Akyuz Ozdemir ORCID: 0000-0001-7882-2563
Ebru Hatice Ayvazoglu Soy ORCID: 0000-0002-0993-9917
Rengin Erdal ORCID: 0000-0002-7329-7576

REFERENCES

1. Gerogianni S, Babatsikou F, et al. Social aspects of renal failure in patients undergoing haemodialysis. Int J Caring Sci 2014;7:740-45.
2. Kimmel P, Patel SS. Quality of life in patients with chronic kidney disease. Focus on the end-stage renal disease treated with hemodialysis. Semin Nephrol 2006;26:68-79.
3. Patel SS, Peterson RA, Kimmel PL. The impact of social support on end-stage renal disease. Semin Dial 2005;18:98-102.
4. Kimmel PL, Emont L, Newmann JM, et al. ESRD patient quality of life: Symptoms, spiritual beliefs, psychosocial factors, and ethnicity. Am J Kidney Dis 2003;42:713-21.
5. Patel S, Shah VS, Peterson RA, et al. Psychosocial variables, quality of life, and religious beliefs in ESRD patients treated with hemodialysis. Am J Kidney Dis 2002;40:1013-22.
6. Kimmel PL. Psychosocial factors in dialysis patients. Kidney Int 2001;59:1599-613.
7. Kimmel PL, Peterson RA, Weihs KL, et al. Multiple measurements of depression predict mortality in a longitudinal study of chronic hemodialysis patients. Kidney Int 2000;57:2093-98.
8. Kimmel PL, Peterson RA, Weihs KL, et al. Psychological functioning, quality of life, and behavioral compliance in patients beginning hemodialysis. J Am Soc Nephrol 1996;7:2152-59.
9. Muehrer JR, Schatell D, Witten B, et al, M. Factors affecting employment at initiation of dialysis. Clin J Am Soc Nephrol 2011;6:489-96.
10. Dingwall R. Living with renal failure: the psychological issues. Edtna Erca J 1997;4:30-5.
11. Pruchno AR, Wilson-Genderson M, Cartwright PF. Depressive symptoms and marital satisfaction in the context of chronic disease: A longitudinal dyadic analysis. J Am Psychol 2009;23:573-84.
12. Sprangers MA, De Regt EB, Andries F. Which chronic conditions are associated with better or poorer quality of life? J Clinl Epidemiol 2000;53:895-907.

13. Zyga S. Chronic kidney disease and quality of life. 9th Panhellenic Conference of Public Health, Athens, Greece 26-28.03.2012

14. Lin CC, Lee BO, Hicks FD. The phenomenology of deciding about hemodialysis among taiwanese. West J Nurs Res 2005;27:915-29.

15. Blake C, Codd MB, Cassidy A, et al. Physical function, employment and quality of life in end-stage renal disease. J Nephrol 2000;13:142-9.

16. Theofilou P. Quality of life and chronic end stage renal failure: a qualitative analysis. Interdisciplinary Health Care 2011;3:70-80.

17. Ryan RM, Brown KW. Why we don't need selfesteem: On fundamental needs, contingent love, and mindfulness. PsychollInq 2003;14:71-6.

18. Paradise AW, Kernis MH. Self-esteem and psychological well-being: implications of fragile self-esteem. J Soc Clin Psych 2002;21:345-49.

19. Tossani E, Cassano P, Fava M. Depression and renal disease. Semin Dial 2005;18:73-81.

20. Drayer RA, Piraino B, Reynolds CF, et al. Characteristics of depression in hemodialysis patients: symptoms, quality of life and mortality risk / Gen Hosp Psychiatry 2006;28:306-12.

21. Kimmel PL, Peterson RA, Weihs KL, et al. Aspects of Quality of Life in Hemodialysis Patients. J Am Soc Nephrol 1995;6:1418-26.

22. Cukor D, Scott D, Cohen Rolf A, et al. Psychosocial Aspects of Chronic Disease: ESRD as a Paradigmatic Illness. J Am Soc Nephrol 2007;18:3042-45.

23. Gerogianni KG. Stressors of patients undergoing chronic hemodialysis. Nursing 2003;42:228-46.

24. Horsburgh ME, Rice VH, Matuk L. Sense of coherence and life satisfaction: Patient and spousal adaptation to home dialysis. ANNA J 1998;25:219-28.

25. Triantaphillopoulou E, Iphou A, Arvaniti P, et al. Psychological nursing support for elderly patients undergoing chronic regular haemodialysis. Edtna Erca J 1998;1:29-31.

26. Dingwall RR. Living with renal failure: the psychological issues. European Dialysis and Transplant Nurses Association/ Eur Renal Care Association J 1997;4:28-30.

27. Gerogianni S, Babatsikou F, Gerogianni G, et al.Concerns of patients on dialysis: a research study .Health Sci J 2014;8:423-37.

28. Kaitelidou D, Liaropoulos L, Siskou O, et al. The social and economic consequences of dialysis in patients' lives with chronic renal insufficiency. Nursing 2007:46:246-55.

29. Özdemir AA, Sayın CB, Erdal R, et al. Quality of life through gender role perspective in candidate renal transplant recipients: a report from başkent university using the short form 36 health survey. Exp Clin Transplant 2018;1:28-34.

30. Özdemir AA, Sayın CB, Erdal R, et al. Influence of social, economic, familial, marital status, and disease adaptation on the physical and mental health dimensions of patients who are candidates for renal transplan. Exp Clin Transplant 2018;1:112-16.

31. Ozdemir AA. Hemodializ tedavisi gören kronik böbrek yetmezliği hastalarının tedavilerinin toplumsal cinsiyet yaklaşımı ile değerlendirilmesi. Doktora Tezi, Ankara, 2016

32. Acaray A, Pınar R. Kronik hemodiyaliz hastalarının yaşam kalitesinin değerlendirilmesi. C.U. Hemşirelik Yüksek Ookulu Dergisi 2004;8:1-11.

33. Seica A, Segall L, Verzan C, et al. Factors affecting the quality of life of haemodialysis patients from Romania: a multicentric study. Nephrol Dial Transplant 2009;24:626-9.

34. Alshraifeen A, McCreaddie M, Evans JM. Quality of life and well-being of people receiving haemodialysis treatment in Scotland: A cross-sectional survey. Int J Nurs Pract 2014;20:518-23.

35. Sathvik BS, Parthasarathi G, Narahani MG et al.An assessment of the quality of life in hemodialysis patients using the WHOQOL-BREF questionnaire. Indian J Nephrol 2008;18:141-9.

36. Moreno F, Lopez Gomez JM, Sanz-Guajardo D, et al. Quality of life in dialysis patients. A spanish multicentre study. Nephrol Dial Transplant 1996;2:125-9.

37. Merkus MP, Jager KJ, Dekker FW, et al. Predictors of poor outcome in chronic dialysis patinets: the netherlands cooperative study on the adequacy of dialysis. The NECOSAD study group. Am J Kidney Dis 2000;35:69-79.

38. Bodenheimer T, Lorig K, Holman H, et al. Patient self-management of chronic disease in primary care. JAMA 2002;288:2469-75.

39. Winkleby M, Jatulis DE, Frank E, et al. Socioeconomic status and health: how education, income, and occupation contribute to risk factors for cardiovascular disease. Am J Public Health 1992;82:816-20.