JMS 2020; 3(2):29-36
UDC: 616.61-008.64-78:364-787.3-055.52

FAMILY SUPPORT IS CRUCIAL FOR DIALYSIS PATIENTS COMPLIANCE TO TREATMENT AND QUALITY OF LIFE

Milenkova Mimoza, Trajceska L, Mladenovska D, Blerim B, Pusevski V, Selim Gj, Rambabova Busljetik I, Spasovski G
University clinic of nephrology, Faculty of Medicine, University "Ss.Cyril and Methodius", Skopje, Republic of North Macedonia

Background**:** Non-compliant dialysis patients are at increased risk of mortality. Compliance and quality of life depends on demographics, education, income, family-support, marital status. Missed dialysis sessions, non-adherence to medications, excessive phosphate levels, inter-dialytic weigh-gain, smoking and non-adherence to medical investigations provide indicators of non-compliance.

Aim**:** Assessing impact of family support on compliance-indicators in dialysis patients.

Methods: 134patients were scored for compliance from 0-2; Summary scores were also assessed. 2-year data was obtained. Patients with mean IDWGs >4.5% and/or phosphorous level above 1.6mmol/L-scored 1, patients with IDWG/BW >5.7%, Pi 2.0mmol/L-scored 2. Summary scores were also assessed. Quality of life scored with SF-36 questionnaire. Non-adherence was analyzed for predictors in multivariate analysis.

Results: Estimated rates of non-compliance varied: medical investigations 63%, phosphorus 33, IDWG 22, therapy 14%, HD treatment 9%. When dietary fluid, medications and treatment regimen were studied, non-compliance rate was 73%, adding adherence to medical investigations rose rate to 87%. Patients with family support above median level (≥25) were significantly more often men (0.049), diabetic (p=0.014), low socioeconomic status (0.001), married (0.003). Poor family support scored significantly worse in quality of life (56.73±26.15*vs*.39.23±24.05, p=0.0001), and overall non-compliance scores 2.04±1.71*vs*.2.97±2.06, p= 0.007). In multivariate analysis non-compliance was predicted best in patients of younger age, low social status, lower family support (β=-0.202, p=0.023, β=0.220, p=0.036, β=-0.175, p=0.019, respectively).

Conclusion: Family support is crucial for patients' compliance to treatment and quality of life. Efforts should be done to meet patients' needs and help those confronting dialysis burden to improve quality of life.

***Key words*:** family support, compliance, dialysis, quality of life, predictors

Introduction

Extensive clinical trials and registry data show significantly high mortality among hemodialysis (HD) patients [1]. There is a major discrepancy between expected results obtained from the general population survival compared to this group of patients. Cardiovascular mortality remains a leading cause for this high mortality [2-4]. Non-traditional risk mortality factors as malnutrition, inflammation and many new factors emerge as potential and modifiable ones. Low compliance (adherence) to treatment and medical advices has already been recognized as a mortality risk in dialysis patients [5-7]. The World Health Organization also warned about the importance of adherence to long-term therapies [8] and recommendations were issued for dialysis patients [9,10].

The most addressed problems were high intradialytic weigh gain (IDWG) [11-16], medications [17], treatment sessions [18] and diet restrictions for potassium and phosphorus [19,20]. The high presence of low compliance induced the need for medical nursing in order to help these patients. Recent meta-analysis showed that nursing intervention is beneficial for raising dialysis compliance, providing evidence to strengthen nursing care for kidney patients administered with dialysis in daily clinical practice [21].

Compared to the general population, dialysis patients have lower health-related quality of life (QoL), which is strongly associated with poorer dialysis adherence, increased hospitalizations, and higher mortality [22-26). Among key attributes of ideal and compliant hemodialysis patients emerge

family support, as stated in NICE and other guidelines [27,28]. In this study we aimed to assess the impact of family support on different compliance indicators in dialysis patients.

Material and methods

In this observational study 134 dialysis patients were scored for different indicators of compliance from 0-2 by and summary scores of compliance were assessed. Clinical, dialysis and laboratory data were obtained from the previous two years. Low socioeconomic status was defined by monthly income <400 euros. Patients with mean IDWGs >4.5% of body weight (BW) and/or phosphorous level above 1.6 mmol/L were scored with 1, patients with IDWG/BW more than 5.7% and/or 2.0 for mean phosphorous level were scored with 2. Patients were questioned for not taking therapy at home, with offered scored answers: never, sometimes and always scored with 0-2. Dialysis regime compliance was scored from 0-2 according to missed/interrupted sessions or missed medical investigations (0 for less than 5%, 1- when more than 15% and 2 when that percentage was over 20%). Summary scores of non-compliance were also assessed, as combined scores for IDWG, therapy regime compliance, and medical investigations. Patients were scored for quality of life with SF-36 questionnaire [29] and family support by Zimet [30].

The comparative analysis was done in the two groups of patients divided by median level of family support scores (below and above 25). Patients non-adherence was analyzed for predictors in a multivariate analysis.

Results

The analyzed patients were aged 55.62 ± 12.90 years with mean dialysis vintage of 112.55 ± 55.11 months. The median level of family support score was 25 and the mean compliance score was 2.49 ± 1.15. The normal distributions of the family support and compliance scores are shown in Figures 1,2.

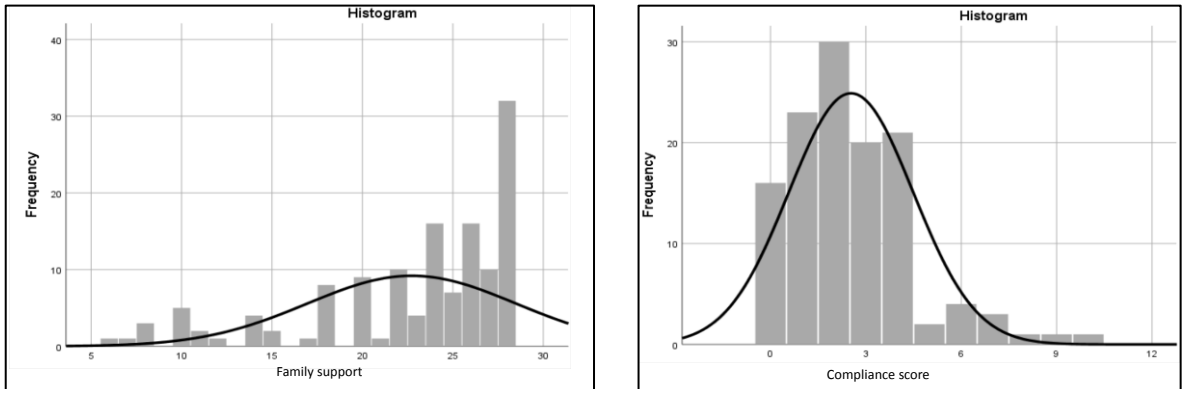

Figure 1,2. Normal distribution of family support and compliance score

Estimated rates of noncompliance varied: medical investigations 63%, phosphorus 33%, IDWG 22%, medicament therapy 14%, HD treatment 9%. When the complete dietary fluid, medications and treatment regimen were studied, non-compliance rate was 73%, and when adherence to medical investigations was added the rate rose up to 87%.

The demographic, clinical and laboratory characteristic of the two groups of patients regarding family support is shown in Table 1. The two groups were comparable in respect of number of patients and did not differ by age, dialysis vintage, dialysis adequacy and presence of smokers.

The nutritional and inflammatory indices as albumin, BMI and CRP also did not differ significantly.

Table 1. Demographic, clinical and laboratory characteristics of the two groups of patients regarding family support

N=134 variable	Family support above median (≥25) N=66	Family support below median (<25) N=68	p
Age (years)	55.52 ± 12.38	55.73 ± 14.19	0.803
Vintage (months)	122.06 ± 68.42	100.06 ± 76.00	0.089
Men	42 (64%)	34 (49%)	0.053
Diabetes	6 (43%)	18 (38%)	0.014
Active smokers	14 (38%)	20 (37%)	0.427
Low socioeconomic status	9 (7%)	30 (29%)	0.001
Low education	35 (57%)	26 (42%)	0.09
Unmarried	9 (13%)	25 (37%)	0.003
Kt/V	1.38 ± 0.21	1.38 ± 0.21	0.832
Albumin (g/L)	39.13 ± 2.43	38.54 ± 2.65	0.733
CRP (ng/ml)	6.75 ± 8.97	7.33 ± 8.51	0.223
BMI (Kg/m^2)	23.62 ± 4.54	23.85 ± 4.72	0.777

Patients with family support above median level (≥25) were significantly more often men (0.049), with diabetes (p=0.014), lower socioeconomic status (0.001) and married (0.003).

As shown in Table 2, all individual quality of life scores were significantly worse in the low family supported patients. The mean component physical score was lower than the mental one, and both were significantly worse in non-supported patients (56.73±26.15 *vs.* 39.23±24.05, p=0.0001; 61.31 ± 22.86 *vs*. 41.68 ± 20.21, p=0.0001, respectively).

Table 2. The quality of life scores of the two groups of patients regarding family support

SF-36 scores	Family support above median (≥25) N=66	Family support below median (<25) N=68	p
Physical functioning	61.38 ± 31.30	43.79 ± 31.95	0.001
Role-physical	54.30 ± 42.61	29.78 ± 39.41	0.017
Bodily pain	70.30 ± 29.78	54.19 ± 31.79	0.002
General health	42.14 ± 18.95	29.99 ± 15.88	0.007
Role Emotional	55.52 ± 25.24	38.41 ± 23.19	0.02
Social functioning	74.41 ± 30.04	47.79 ± 29.24	0.001
Vitality	70.83 ± 36.65	44.64 ± 40.59	0.0001
Mental health	63.27 ± 19.37	47.01 ± 17.66	0.001
Physical component score (PCS)	**56.73 ± 26.15**	**39.23 ± 24.05**	**0.0001**
Mental component score (MCS)	**61.31 ± 22.86**	**41.68 ± 20.21**	**0.0001**

Regarding the patients compliance (Table 3), the dialysis regime was respected in the same manner in the two groups of patients, but adherence to therapy, IDWG and medical investigations was far more better when patients had family support. Those with lower family support also scored worse in overall non-compliance scores (2.04±1.71 *vs*. 2.97±2.06, p= 0.007, respectively).

The family support showed a strong inverse correlation with non-compliance as shown in Figure 3.

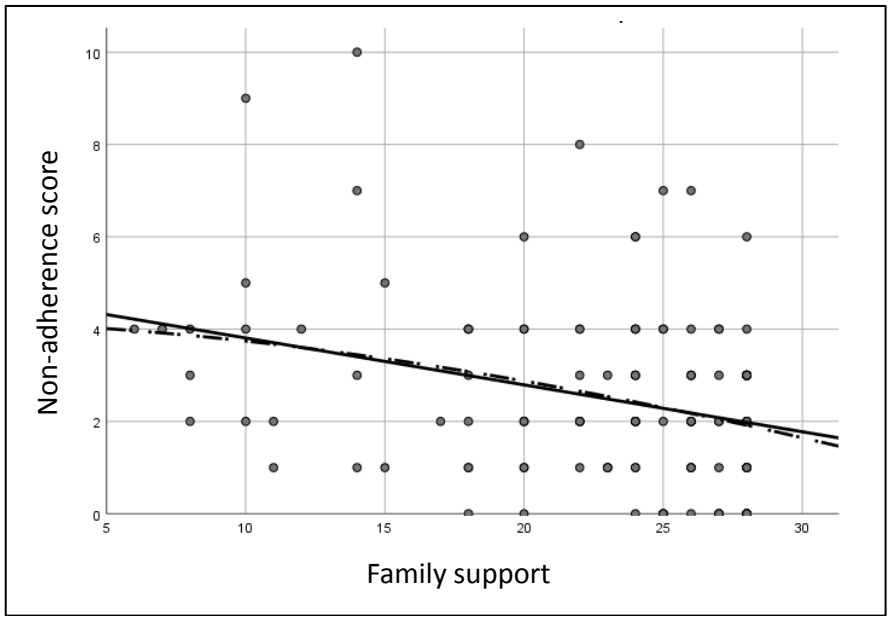

Figure 3. Family support score in correlation with non-adherence score

Table 3. Compliance scores according to family support

Compliance	Family support above median (≥25) N=66	Family support below median (<25) N=68	p
Therapy with medications	0.07 ± 0.32	0.25 ± 0.56	0.039
Dialysis regime	0.05 ± 0.29	0.18 ± 0.52	0.086
IDWG/BW	0.95 ± 0.84	0.84 ± 0.85	0.054
Medical investigations	0.58 ± 0.75	1.20 ± 0.75	0.0001
Compliance score	**2.04 ± 1.71**	**2.97 ± 2.06**	**0.007**

In the univariate analysis, the non-compliance predictors were: lower family support, younger age, lower social status and unmarried status (Table 4).

Table 4. Univariate analysis of non-compliance predictors

Low compliance Univariate analysis	**β**	**p**
Family support	-0.301	0.0001
Male gender	-0.053	0.563
Age	-0.272	0.002
Education level	0.118	0.196
Vintage	-0.017	0.849
Marriage	-0.201	0.026
Social status	0.373	0.0001

In the multivariate analysis, the non-compliance was predicted most powerfully in patients with younger age, low social status and lower family support (β=-0.202, p=0.023, β=0.220, p=0.036, β=-0.175, p=0.019, respectively). As most powerful predictors of low compliance, the low family support, younger age and low economic status emerged from the multivariate analysis (Table 5.)

Table 5. Multivariate analysis of non-compliance predictors

Low compliance Multivariate analysis	**β**	**p**
Family support	-0.175	0.019
Age	-0.202	0.023
Social status	0.220	0.036

Discussion

The importance of studding compliance in dialysis patients and the need for providing evidence of influential and modifiable factors causing it, emerge from large scientific data on the causative role of non-compliance on mortality. The proportions of non-compliance presented in several studies were high and wide. Our results were closer to studies showing lower percentages. The prevalence of non-adherence to fluid restriction ranged from 30 - 70% in Leggats study [11] and we found it less than quarter (22%) in our patients. Also, estimates of non-adherence to the dietary regimen ranged from 19 - 57% for phosphate intake in Gerbinos study [19], and we noted it in 33% of patients and for other medications in 14%. Skipping dialysis sessions was observed in only 9% and the DOPPS study [5]found it in up to 32% of dialysis patients. All these lower percentages of non-adherence motivated us to seek for another factor influencing compliance. In our study, we addressed the family support as possibly connected to the compliance of dialysis patients. We studied two groups of patients comparable by age and dialysis vintage , divided by family support median score. We hypothesized that patients supported and rounded by family were more compliant and had better quality of life. The scores of family support in vast majority of our patients were high, which maybe a result of the nature of our traditional family ties and larger number of home family members living together.

We found better scores of family support in men, patients with diabetes, those with spouse and lower socioeconomic status. Men and women respond differently to stress. Women faced with a stressful situation are more likely to respond by socializing, bonding with others, and seeking protection and nurturance within a community [31-33]. Men who have marital partners also live longer than men without spouses [34]. A major survey of 127,545 American adults found that married men are healthier [35]. Men and unmarried, therefore, need more family support, as we found in our study as well. Patients with diabetes gained more family support. That might be caused by many early and severe complications that endure those patients, with a need of support and care.

Regarding the quality of life scores, our results were in line with other studies [36,37]. Patients with better family support also achieved better QoL which confirmed our hypothesis. Generally, mental scores were higher than physical ones, which was in line with other studies.

When we analyzed compliance, the dialysis regime was respected in the same manner in the two groups of patients, but adherence to therapy, IDWG and medical investigations was far better when patients had family support. Those with lower family support also scored worse in overall non-compliance scores. The compliance was highly correlated to family support. This finding of ours was also confirmed in studies on adherence to medical treatment in diabetics and hypertensive patients [38,39].

The final analysis of predictors of compliance emphasized the family support among the most powerful factors. Patients that were younger and with lower economic status were presented as the most vulnerable to low compliance. These findings must alarm us to protect those patients with additional social measures, providing help, support and continuous surveillance and education.

Conclusion

Family support is crucial for dialysis patients compliance to medical therapy and life quality. Care providers and patients should be informed about the need and potential benefits of family, social

and psychological support. Efforts should be done to prevent and take care of the non-compliance issue.

Reference

1. Kramer A, Pippias M, Noordzij M, Stel V, Andrusev A, Aparicio-Madre M et al. The European Renal Association – European Dialysis and Transplant Association (ERA-EDTA) Registry. Annual Report 2016. Clinical Kidney Journal, 2019, 1–19
2. Ahmadmehrabi S, Tang WHW. Hemodialysis-induced cardiovascular disease. Semin Dial. 2018;31(3):258–67
3. Collins AJ, et al. United States Renal Data System 2011 Annual Data Report: Atlas of chronic kidney disease & end-stage renal disease in the United States. American Journal of Kidney Diseases. 2012;59(1):A7, 1-420
4. Roberts MA, et al. Secular trends in cardiovascular mortality rates of patients receiving dialysis compared with the general population. American Journal of Kidney Diseases. 2011;58(1):64-72
5. Saran R, Bragg-Gresham JL, Rayner HC, Goodkin DA, Keen ML, Van Dijk PC, Kurokawa K, Piera L, Saito A, Fukuhara S, et al: Nonadherence in hemodialysis: associations with mortality, hospitalization, and practice patterns in the DOPPS. Kidney Int 2003; 64: 254–62.
6. Sharp J, Wild MR, Gumley AI, Deighan CJ: A cognitive behavioral group approach to enhance adherence to hemodialysis fluid restrictions: a randomized controlled trial. Am J Kidney Dis 2005; 45: 1046–57.
7. Vlaminck H, Maes B, Jacobs A, Reyntjens S, Evers G. The dialysis diet and fluid non adherence questionnaire: Validity testing of a self-report instrument for clinical practice. J Clin Nurs 2001;10:707-15.
8. World Health Organization: Adherence to Long-Term Therapies. Evidence for Action. Geneva, World Health Organization, 2003.
9. Pierratos A, McFarlane P, Chan CT, Kwok S, Nesrallah G: Daily hemodialysis 2006. State of the art. Minerva Urol Nefrol 2006; 58: 99–115.
10. Depner TA, Daugirdas JT: Clinical Practice Guidelines and Clinical Practice Recommendations 2006 Updates Hemodialysis Adequacy Peritoneal Dialysis Adequacy Vascular Access, 2006.
11. Leggat JE, Orzol SM, Hulbert-Shearon TE, et al. Noncompliance in hemodialysis: Predictors and survival analysis. Am J Kidney Dis 2004; 32:139-45.
12. Lindberg M, Prutz KG, Lindberg P, Wikstrom B. Interdialytic weight gain and ultrafiltration rate in hemodialysis: Lessons about fluid adherence from national registry of clinical practice. Hemodial Int 2009;13:181-8.
13. Leggat JE, Orzol SM, Hulbert-Shearon TE, et al. Noncompliance in hemodialysis: Predictors and survival analysis. Am J Kidney Dis 2004; 32:139-45.
14. Sharp J, Wild MR, Gumley AI, Deighan CJ: A cognitive behavioral group approach to enhance adherence to hemodialysis fluid restrictions: a randomized controlled trial. Am J Kidney Dis 2005; 45: 1046–57.
15. Hare J, Clark-Carter D, Forshaw M: A randomized controlled trial to evaluate the effectiveness of a cognitive behavioral group approach to improve patient adherence to peritoneal dialysis fluid restrictions: a Pilot study. Nephrol Dial Transplant 2014; 29: 555–64.
16. Howren MB, Kellerman QD, Hillis SL, Cvengros J, Lawton W, Christensen AJ: Effect of a behavioral self-regulation intervention on patient adherence to fluid-intake restrictions in hemodialysis: a randomized controlled trial. Ann Behav Med 2016; 50: 167–76.
17. Karamanidou C, Clatworthy J, Weinman J, Horne R. A systematic review of prevalence and determinants of nonadherence to phosphate binding medication in patients with end stage renal disease. BMC Nephrol 2008;9:1-10.
18. Saran R, Bragg-Gresham JL, Rayner HC, et al. Nonadherence in hemodialysis: Associations with mortality, hospitalization, and practice patterns in the DOPPS. Kidney Int 2003;64: 254-62.
19. Gerbino G, Dimonte V, Albasi C, Lasorsa C, Vitale C, Marangella M. Adherence to therapy in patients on hemodialysis. G Ital Nephrol 2011;28:416-24.

20. Stamatakis MK, Pecora PG, Gunel E. Factors influencing adherence in chronic dialysis patients with hyperphosphatemia. J Ren Nutr 1997;7:144-8.
21. Wang J, Yue P, Huang J, Xie X, Ling Y, Jia L, Xiong Y, Sun F: Nursing Intervention on the Compliance of Hemodialysis Patients with End-Stage Renal Disease: A Meta-Analysis. Blood Purif 2018;45:102-9.
22. Fukuhara S, Lopes AA, Bragg-Gresham JL, Kurokawa K, Mapes DL, Akizawa T, Bommer J, Canaud BJ, Port FK, Held PJ. Health-related quality of life among dialysis patients on three continents: the Dialysis Outcomes and Practice Patterns Study. Kidney Int. 2003;64(5):1903–10.
23. Mapes DL, Lopes AA, Satayathum S, McCullough KP, Goodkin DA, Locatelli F, Fukuhara S, Young EW, Kurokawa K, Saito A, et al. Health-related quality of life as a predictor of mortality and hospitalization: the Dialysis Outcomes and Practice Patterns Study (DOPPS). Kidney Int. 2003;64(1):339–49.
24. Akman B, Uyar M, Afsar B, Sezer S, Ozdemir FN, Haberal M. Adherence, depression and quality of life in patients on a renal transplantation waiting list. Transpl Int. 2007;20(8):682–7.
25. Eneanya, N.D., Maddux, D.W., Reviriego-Mendoza, M.M. et al. Longitudinal patterns of health-related quality of life and dialysis modality: a national cohort study. BMC Nephrol 20, 7 (2019). https://doi.org/10.1186/s12882-018-1198-5
26. Ibrahim S, Mohammed H, Dawalt B. Study of non-compliance among chronic hemodialysis patients and its impact on patients' outcomes.2015; 3 (1):243-9
27. Schatell D. MATCH-D: a roadmap to home dialysis therapy. Nephrol News Issues. 2007;21(11):41,43-4
28. Renal replacement therapy and conservative management. NICE 2019. https://www.nice.org.uk
29. Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). Med Care 1992; 0:473-83
30. Zimet G. Powell S, Farley G, Werkman S, Berkoff K. Psychometric properties of the multidimensional scale of perceived social support. Journal of personality assessment. 1990;55:610-7
31. Taylor, S. E. Social support: A review. Oxford Handbook of Health Psychology. New York, NY: 2011;Oxford University Press.
32. Eisenberger, N. I., Way, B. M., Taylor, S. E., Welch, W. T., & Lieberman, M. D. MAOA, gender differences, and social exclusion: Response to Gallardo-Pujol et al. Biological Psychiatry,2008; 63, e11.
33. Taylor, S.E. & Gonzaga, G. Affiliative responses to stress: A social neuroscience model. Tend and befriend: Biobehavioral bases of affiliation under stress. Current Directions in Psychological Science, 2006;215, 273-7
34. Olga Stavrova. Having a happy spouse is associated with lowered risk of mortality. Psychological Science, 2019; 095679761983514 DOI: 10.1177/0956797619835147
35. Harvard Men's Health Watch, "Marriage And Men's Health," July 2010, accessed at www.health.harvard.edu/newsletters/Harvard_Mens_Health_Watch/2010/July/marriage-and-mens health ? utm_source=mens&utm_medium+pressrelease&utm_campaign+mens0710, on July 19, 2010.
36. Kaur H, Kaur H, Venkateashan M. Factors determining family support and quality of life of elderly population. Int J Med Sci Public Health 2015;4:1049-53
37. Prazeres, F., Santiago, L. Relationship between health-related quality of life, perceived family support and unmet health needs in adult patients with multimorbidity attending primary care in Portugal: a multicentre cross-sectional study. Health Qual Life Outcomes 2016; 14**,** 156. https://doi.org/10.1186/s12955-016-0559-7

38. Miller TA, Dimatteo MR. Importance of family/social support and impact on adherence to diabetic therapy. Diabetes Metab Syndr Obes. 2013;6:421- 426. Published 2013 Nov 6. doi:10.2147/DMSO.S36368
39. Kurniawati N, Wahyuni D, Toulasik, Y. Family Support Improves Hypertensive Patient Drug Compliance. Indian Journal of Public Health Research & Development 2019;2260 DO - 10.5958/0976-5506.2019.02270.8