

Health Related Quality of Life in Chronic Kidney Disease Patients

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Abstract

Chronic Kidney Disease (CKD) and especially End-Stage Renal Disease (ESRD) have a detrimental effect on both patients' life expectancy, as well as on Health Related Quality of Life (HRQOL). The detrimental effects of ESRD and dialysis treatment on HRQOL have been confirmed on three different continents. However, there are some international differences in HRQOL scores. Japanese patients seem to have better physical functioning than the patients from the United States and Europe. On the other hand, United States patients score higher in mental component summary. Additionally, Japanese patients report the greatest burden for kidney disease. Physical Component Summary (PCS), Mental Component (MCS) and Kidney Disease Component Summary (KDSCS), have been found to be strongly associated with higher risk of death and hospitalization in hemodialysis patients independent of demographic and comorbid factors. It has been observed that peritoneal dialysis patients present less bodily pain, better traveling possibilities, less diet restriction, less burden regarding dialysis access, as well as higher scores in physical functioning and emotional problems at the initiation of dialysis treatment. On the other hand, HD patients tend to show greater improvement in time as regards physical functioning, general health perceptions, sleep and global quality of life. It is of no surprise the fact that patients after successful kidney transplantation report QOL which is comparable to that of healthy volunteers.

Keywords: Chronic kidney disease; Quality of life

Introduction in QOL

It has already been more than half a century since World Health Organization defined health as a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity [1]. Chronic Kidney Disease (CKD) and especially End-Stage Renal Disease (ESRD) have a detrimental effect on patients' life expectancy, as well as on Health Related Quality of Life (HRQOL) [2].

QOL Characteristics in CKD

A rapid literature review in general data-bases like "pubmed" will reveal less than three articles related with Quality of Life (QOL) by the seventies; by the eighties their total number became more than two thousands, to reach 170,000 by 2012. In five thousand of these articles there is some kind of relation - connection with CKD. Obviously, there is a mounting body of interest regarding HRQOL. This is more or less expected since our primary goal is to treat patients, and our aim is also to improve psychological and social domains of health. These domains are greatly influenced by a person's experiences, beliefs, expectations and perceptions. This interest reflects a more "holistic" approach of health. It represents contemporary attempt to improve both physical and mental health status. Since complete cure does not always represent a realistic goal, as in the case of chronic diseases like CKD, possible ways to assess and improve HRQOL gain increasing importance. This need to estimate QOL in various diseases, led to the development of numerous disease specific instruments. What should be the major characteristics of the QOL instruments? They should show adequate sensitivity (the ability to reflect true changes when they really exist), responsiveness (a measured change in QOL score should reflect a true change in patient's health status), validity (they should measure what they intended to measure), and reliability (their results should be consistent and should remain similar under reasonably stable conditions) [3,4]. Among them we can find instruments for the assessment of health status in diabetic patients [5], patients suffering from arthritis [6], or ankylosing spondylitis [7], and even for patients suffering from benign prostatic hyperplasia [8]. Not long after these initial attempts, kidney disease quality of life (KDQOL) instrument [9] was developed. The most commonly used variant in CKD patients is the kidney disease quality of life-short form (KDQOL-SF) questionnaire [3,10].

KDQOL-SF Questionnaire

KDQOL-SF questionnaire has been consequently culturally adapted and validated in various languages [11-13]. The KDQOL-SF questionnaire comprises two major parts; a generic part, consisting of a 36 - item form, known as SF-36 (Short Form - 36) questionnaire, and a part specifically developed for renal patients. The complete form of the questionnaire contains almost 100 questions summarized in 20 major components and 3 major component summaries (Table 1). Questionnaires' scoring is based on a Likert scale (i.e. for each possible answer is given a score from 0 to 12, according to the total number of possible answers), this score is then linearly transformed from 0 to 100, conferring the final score. The higher the score is, the better the quality of life. Any statistically significant difference observed is not by definition clinically important. Nevertheless, it might be generally advisable not to take into consideration differences < 3 points [14,15].

Results of Quality of Life Assessment in CKD

Quality of life assessment as treatment/outcome - control instrument was initially used during the introduction of recombinant human erythropoietin in the treatment of patients with end-stage renal disease [16]. In this historical study, the author concluded that there was a substantial improvement in the quality of hemodialysis patients who received erythropoietin. Improvement which was evident on most objective and subjective quality of life parameters, as energy, functional ability, sleep, disease symptoms, health status, sex life and general well-being.

Both late diagnosis of chronic renal disease and late referral of CKD

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SF-36	Physical functioning
	Role physical
	Bodily pain
	General health
Physical component summary	Vitality
	Social functioning
	Role emotional
	Mental health
Mental component summary	Mental component
Kidney disease component summary	Symptoms, problems
	Effects
	Burden
	Work status
	Cognitive functioning
	Quality social
	Sexual functioning
	Sleep
	Social support
	Staff encouragement
	Satisfaction

Table 1: Health related quality of life components.

patients to the nephrologist are associated with increased morbidity and mortality [17,18]. Moreover, late diagnosis of CKD has been shown to have a 2.8 times greater mortality risk compared to early diagnosis [19]. When QOL was estimated in these patients, a worse score was observed in almost all measures in the late – diagnosis group compared to the early – diagnosis group [20]. These differences were proven both clinically and statistically significant in the depression, relationships and frustration dimensions of the KDQOL. Furthermore, health and life – satisfaction indices were significantly worse in the late – diagnosis group when compared to one year prior to dialysis [20], findings which remained constant both for elderly and younger patients.

The detrimental effects of ESRD and dialysis treatment of HRQOL have been confirmed on three different continents [2]. A significant correlation was observed between KDQOL and hospitalization in CKD patients [9]. However, there are some international differences in HRQOL scores. Japanese patients seem to have better physical than the patients from the United States and Europe. On the other hand, United States patients score higher in mental component summary and mental health. Additionally, Japanese patients report the greatest burden for kidney disease [2]. Physical component summary (PCS), mental component (MCS) and kidney disease component summary (KDSC), have been found to be strongly associated with higher risk of death and hospitalization in hemodialysis patients, independent of demographic and comorbid factors [21]. Moreover, it was estimated that for each 10-point lower score in PCS, MCS and KDSC, mortality risk increased 25%, 13% and 11% respectively [21].

Among other morbid conditions, depression is known to have a strong impact on HRQOL in predialysis CKD patients [22], as well as in ESRD patients receiving dialysis [23]. This is an expected finding, since patients suffering from severe chronic kidney disease are called to cope with a variety of chronic recurrent stressors. Advanced kidney disease significantly affects patient’s life style; patients are expected to follow certain nutritional restrictions; arteriovenous fistula creation or catheter insertion will inevitably change their day to day life; and finally they will need to follow a predefined dialysis program. Obviously, chronic kidney disease threatens and affects patient’s personal control of their life. Unfortunately, depression will not affect only CKD patients as if they were an isolated entity. It has been observed that during the

first couple of years after the initiation of dialysis, depression reaches high levels and then decreases, presenting inevitably a similar variation in their spouses [24].

HRQOL has been also studied in patients on peritoneal dialysis (PD), even though to a lesser extent. Among studied parameters, intensified peritoneal dialysis program aiming at a better peritoneal small – solute clearance was not proven to have a long – term benefit in HRQOL when compared to standard peritoneal dialysis treatment [25]. Nonetheless, HRQOL scores have been highly predictive of peritoneal dialysis patients hospitalization and survival [25,26]. Additionally, it was observed in PD patients that older age [25,26], lower starting glomerular filtration rate [25], female gender [25,26], altered nutritional status (usually expressed by a lower albumin level) and poor residual renal function [25-27], are invariably associated with worse HRQOL. Patients receiving peritoneal dialysis, like patients on hemodialysis, will finally experience a decline in HRQOL [26].

Different medical programs and treatments have a different impact on patients’ quality of life and their effects should not be ignored simply because they are difficult to assess [28]. Furthermore, their cost effectiveness might vary significantly and could even be reversed when adjusting effectiveness for quality of life [29].

It has been speculated that high dose and high flux hemodialysis treatment would affect quality of life. The HEMO study examined the QOL changes attributed to hemodialysis dose and membrane flux as a secondary study outcome [30]. The authors observed a slower decline in bodily pain in the high – dose group of patients. High flux patients reported also better sleep and greater patient satisfaction compared to low flux patients. Nevertheless, the observed effects did not meet the stricter significance criterion (Bonferoni correction in this case), and should be interpreted only as hypothesis generating.

Depression is a significant predictor of mortality and hospitalization in ESRD patients and can be roughly approached with HRQOL instruments [31]. Additionally, there is data suggesting a heavier depression burden of HD compared to PD patients [32].

In dialysis patients, age has been shown to be inversely correlated with physical fitness and daily activities [33]. Similarly, time of dialysis treatment and comorbidity index (presence of comorbid conditions is usually assessed as a sum of co-existing diseases [34]) have been found to be inversely correlated with physical fitness, daily activities and overall health [35].

Peritoneal dialysis or hemodialysis? Is there a unique and absolute answer to the patient’s question, at least regarding QOL? It seems that there isn’t one. It has been observed that PD patients present less bodily pain, better traveling possibilities, and fewer diet restrictions, less burden regarding dialysis access, as well as higher scores in physical functioning and emotional problems at the initiation of dialysis treatment. On the other hand, HD patients tend to show greater improvement in time as regards physical functioning; general health perceptions, sleep and global quality of life [35]. Obviously there are distinct differences between the two modalities. For example, if a patient is more concerned about his/her ability to work, wants to experience less pain and less diet restrictions, it might be better to chose peritoneal dialysis. On the other hand, if other aspects of life are considered more significant and sleep quality or sexual functioning are a top priority, then it might be better to consider hemodialysis [35].

Health related quality of life has been successfully used to assess both disease and treatment effects on patients’ lives [16,36]. Could it explore the type of provided health care or even compare different

health care programs? It seems that CKD patients on a Managed Care Program (MCP) are less satisfied than Free-For-Service (FFS) patients as regards access to health care providers, but more satisfied with the financial benefits (copayment coverage, prescription drugs and nutritional supplements) [37]. Researchers conclude that quality of life analyses have important implications for evaluating the success of health care providers.

Each and every time a questionnaire is distributed to healthy volunteers or patients; there is a significant number of them who will either refuse to answer or will not be able to, due to various reasons. What happens to the patients who will not answer the HRQOL questionnaire? In a large scale study in hemodialysis patients (DOPPS) [21], it was observed that more than seven thousand patients provided an incomplete response or no response at all, while ten thousand patients answered all questions. Furthermore, patients who gave an incomplete/or no response at all, presented more than twice higher risk of death (RR=2.51, 95% CI=2.35 to 2.69; $p < 0.001$) and a 33% higher risk of hospitalization (RR=1.33, 95% CI=1.26 to 1.41; $p < 0.001$).

Beyond traditional factors, there is increasing interest regarding other non-traditional, possibly modifiable factors that affect HRQOL. Among them, Secondary Hyperparathyroidism (SHPT) gains the interest of many researchers [13,38]. Fortunately, even though SHPT affects HRQOL in ESRD patients, its treatment seems to improve bodily pain and physical component score [13,38].

Interest in HRQOL estimation is not restricted to patients receiving hemodialysis or peritoneal dialysis treatment. Similarly to HD and PD, various QOL questionnaires have been adapted, validated and used in kidney transplanted patients [39]. It is of no surprise the fact that patients after successful kidney transplantation report QOL which is comparable to that of healthy volunteers [40].

Conclusion

Chronic kidney disease and especially end-stage renal disease have a detrimental effect on both patients' life expectancy, and health related quality of life. Our permanent goal should be to cope with both targets.

References

1. Constitution of the World Health Organization (1952) In: World Health Organization Handbook of basic documents.
2. Fukuhara S, Lopes AA, Bragg-Gresham JL, Kurokawa K, Mapes DL, et al. (2003) Health-related quality of life among dialysis patients on three continents: the Dialysis Outcomes and Practice Patterns Study. *Kidney Int* 64: 1903-1910.
3. Hays RD, Kallich JD, Mapes DL, Coons SJ, Amin N, et al. (1996) Kidney Disease Quality of Life Short Form (KDQOL-SF) Version 1.3: A manual for use and scoring. Santa Monica, Washington, D.C., USA.
4. Laupacis A, Muirhead N, Keown P, Wong C, et al. (1992) A disease-specific questionnaire for assessing quality of life in patients on hemodialysis. *Nephrol* 60: 302-306.
5. Hammond GS, Aoki TT (1992) Measurement of health status in diabetic patients: Diabetes impact measurement scales. *Diabetes Care* 15: 469-477.
6. Meenan RF, Mason JH, Anderson JJ, Guccione AA, Kazis LE (1992) AIMS2. The content and properties of a revised and expanded Arthritis Impact Measurement Scales Health Status Questionnaire. *Arthritis Rheum* 35: 1-10.
7. Doward LC, McKenna SP, Meads DM, Twiss J, Revicki D, et al. (2007) Translation and validation of non-English versions of the Ankylosing Spondylitis Quality of Life (ASQOL) questionnaire. *Health Qual Life Outcomes* 5:7.
8. Epstein RS, Deverka PA, Chute CG, Panser L, Oesterling JE, et al. (1992) Validation of a new quality of life questionnaire for benign prostatic hyperplasia. *J Clin Epidemiol* 45: 1431-1445.
9. Hays RD, Kallich JD, Mapes DL, Coons SJ, Carter WB (1994) Development of the kidney disease quality of life (KDQOL) instrument. *Qual Life Res* 3: 329-338.

10. Valderrabano F, Jofre R, Lopez-Gomez JM (2001) Quality of life in end-stage renal disease patients. *Am J Kidney Dis* 38: 443-464.
11. Green J, Fukuhara S, Shinzato T, Miura Y, Wada S, et al. (2001) Translation, cultural adaptation, and initial reliability and multitrait testing of the Kidney Disease Quality of Life instrument for use in Japan. *Qual Life Res* 10: 93-100.
12. Klersy C, Callegari A, Giorgi I, Sepe V, Efficace E, et al. (2007) Italian translation, cultural adaptation and validation of KDQOL-SF, version 1.3, in patients with severe renal failure. *J Nephrol* 20: 43-51.
13. Malindretos P, Sarafidis P, Spaia S, Sioulis A, Zeggos N, et al. (2010) Adaptation and Validation of the Kidney Disease Quality of Life-Short Form Questionnaire in the Greek Language. *Am J Nephrol* 31: 9-14.
14. Hays RD, Woolley JM (2000) The concept of Clinically Meaningful Difference in Health - Related Quality - of - Life Research. How Meaningful Is It? *Pharmacoeconomics* 18: 419-423.
15. Samsa G, Edelman D, Rothman ML, Williams GR, Lipscomb J, et al. (1999) Determining clinically important differences in health status measures: a general approach with illustration to the Health Utilities Index Mark II. *Pharmacoeconomics* 15: 141-155.
16. Evans RW, Rader B, Manninen DL (1990) The quality of life of hemodialysis recipients treated with recombinant human erythropoietin. Cooperative Multicenter EPO Clinical Trial Group. *JAMA* 263:825-830.
17. Ratcliffe PJ, Phillips RE, Oliver DO (1984) Late referral for maintenance dialysis. *Br Med J (Clin Res Ed)* 288: 441-443.
18. Jungers P, Zingraff J, Albouze G, Chauveau P, Page B, et al. (1993) Late referral to maintenance dialysis: detrimental consequences. *Nephrol Dial Transplant* 8: 1089-1093.
19. Sesso R, Belasco AG (1996) Late diagnosis of chronic renal failure and mortality on maintenance dialysis. *Nephrol Dial Transplant* 11: 2417-2420.
20. Sesso R, Yoshihiro MM (1997) Time of diagnosis of chronic renal failure and assessment of quality of life in haemodialysis patients. *Nephrol Dial Transplant* 12: 2111-2116.
21. Mapes DL, Lopes AA, Satayathum S, McCullough KP, Goodkin DA, et al. (2003) Health-related quality of life as a predictor of mortality and hospitalization: the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Kidney Int* 64: 339-349.
22. Simmons RG, Abress L (1990) Quality-of-life issues for end-stage renal disease patients. *Am J Kidney Dis* 15: 201-208.
23. Kimmel PL, Peterson RA, Weihs KL, Simmens SJ, Boyle DH, et al. (1996) Psychologic functioning, quality of life, and behavioral compliance in patients beginning hemodialysis. *J Am Soc Nephrol* 7: 2152-2159.
24. Biris A, Messinis L, Antoniadis G, Skarli V (2002) Quality of life, spouse marital adjustment and depression in a sample of end-stage renal disease (ESRD) patients in Greece. *Hippokratia* 6: 56-61.
25. Paniagua R, Amato D, Vonesh E, Guo A, Mujais S, et al. (2005) Health-related quality of life predicts outcomes but is not affected by peritoneal clearance: The ADEMEX trial. *Kidney Int* 67: 1093-1104.
26. Bakewell AB, Higgins RM, Edmunds ME (2002) Quality of life in peritoneal dialysis patients: Decline over time and association with clinical outcomes. *Kidney Int* 61: 239-248.
27. Merkus MP, Jager KJ, Dekker FW, de Haan RJ, Boeschoten EW, et al. (1999) Physical symptoms and quality of life in patients on chronic dialysis: results of The Netherlands Cooperative Study on Adequacy of Dialysis (NECOSAD). *Nephrol Dial Transplant* 14:1163-1170.
28. Testa MA, Lenderking WR (1992) Interpreting pharmacoeconomic and quality-of-life clinical trial data for use in therapeutics. *Pharmacoeconomics* 2: 107-117.
29. Testa MA, Simonson DC (1996) Assessment of quality-of-life outcomes. *N Engl J Med* 334: 835-840.
30. Unruh M, Benz R, Greene T, Yan G, Beddhu S, et al. (2004) Effects of hemodialysis dose and membrane flux on health-related quality of life in the HEMO Study. *Kidney Int* 66: 355-366.
31. Lopes AA, Bragg J, Young E, Goodkin D, Mapes D, et al. (2002) Depression as a predictor of mortality and hospitalization among hemodialysis patients in the United States and Europe. *Kidney Int* 62: 199-207.
32. Theofilou P (2011) Quality of life in patients undergoing hemodialysis or peritoneal dialysis treatment. *J Clin Med Res* 3:132-138.

33. Martin-Diaz F, Reig-Ferrer A, Ferrer-Cascales R (2006) Assessment of health-related quality of life in chronic dialysis patients with the COOP/WONCA charts. *Nephron Clin Pract* 104: c7-14.
34. Athienites NV, Miskulin DC, Fernandez G, Bunnapradist S, Simon G, et al. (2000) Comorbidity assessment in hemodialysis and peritoneal dialysis using the index of coexistent disease. *Semin Dial* 13: 320-326.
35. Wu AW, Fink NE, Marsh-Manzi JV, Meyer KB, Finkelstein FO, et al. (2004) Changes in quality of life during hemodialysis and peritoneal dialysis treatment: generic and disease specific measures. *J Am Soc Nephrol* 15:743-753.
36. Malindretos P, Sarafidis P, Lazaridis A, Nikolaidis P (2012) A study of the association of higher parathormone levels with health-related quality of life in hemodialysis patients. *Clin Nephrol* 77: 196-203.
37. Pifer TB, Bragg-Gresham JL, Dykstra DM, Shapiro JR, Oppenheimer CC, et al. (2003) Quality of life and patient satisfaction: ESRD managed care demonstration. *Health Care Financ Rev* 24: 45-58.
38. Cunningham J, Danese M, Olson K, Klassen P, Chertow GM (2005) Effects of the calcimimetic cinacalcet HCl on cardiovascular disease, fracture, and health-related quality of life in secondary hyperparathyroidism. *Kidney Int* 68: 1793-1800.
39. Franke GH, Reimer J, Kohnle M, Luetkes P, Maehner N, et al. (1999) Quality of life in end-stage renal disease patients after successful kidney transplantation: development of the ESRD symptom checklist - transplantation module. *Nephron* 83: 31-39.
40. Franke GH, Heemann U, Kohnle M, Luetkes P, Maehner N, et al. (2000) Quality of life in patients before and after kidney transplantation. *Psychol Health* 14: 1037-1049.

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