ORIGINAL PAPERS: CLINICAL OR BASIC RESEARCH

A longitudinal study on changes in quality of life and illness representations in long-term hemodialysis patients with low comorbidity

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ABSTRACT

Background. *Quality of life (QoL) scores are associated with mortality and hospitalization in hemodialysis (HD) patients. There are very few longitudinal studies in HD patients describing changes in QoL and no prospective study assessing the dynamics of both QoL and illness representations, over a significantly long follow-up period. Therefore, the main objective of our study was to describe for the first time in a group of well-dialysed patients the dynamics of both quality of life and illness representations over a significantly long follow-up period and to investigate the relationship between these two dynamics.*

Methods. *81 clinically stable HD patients completed at baseline and after 2 years* The Revised Illness Perception Questionnaire (IPQ-R) *and* The Short Form Health Survey Questionnaire (SF-36). *The changes in hemoglobin (Hb), serum phosphate, parathormone and Kt/V over the 2 years interval were computed and used as independent variables.*

Results. *Overall QoL scores improved over the 2 years period. The physical component score (PCS) improved from 46 to 52.8 (p<0.01) while a non-significant positive trend was observed for the mental component score (from 51.3 to 54.4, p=ns). Patients' beliefs improved in 3 out of the 6 evaluated dimensions: understanding of the illness (p=0.003), treatment control (p=0.02) and the emotional reaction to the disease (p=0.002). Multivariate regression analyses were computed to evaluate the change in scores observed for both PCS and MCS. After adjusting for baseline QoL status and changes in biochemical parameters, the dynamics in QoL over the 2-year follow-up period are predicted by baseline illness representations. The final model explains > 80% of the variance in DPCS and DMCS. Of note, the baseline emotional response, personal control and coherence account for 51% of the variance in DPCS, while a single dimension – disease consequences – accounts for 39% of the variance in DMCS.*

Conclusion. *Quality of life scores are best understood together with the description of patients' individual models of illness.*

Key words: end-stage renal disease, hemodialysis, illness representations, quality of life

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INTRODUCTION

End-stage renal disease patients have a high burden of disease (particularly cardiovascular comorbidities) affecting their quality of life (QoL) and dramatically shortening life expectancy (1). Therefore, exploring QoL becomes an essential task in the management of this population.

There is growing evidence that *The MOS Short Form Health Survey Questionnaire* (SF-36) has become a valuable tool in clinical care, detecting the risk of mortality and hospitalization in hemodialysis patients (2-5). SF-36 proved over time to be a reliable and valid instrument for measuring eight domains of health-related QoL: physical functioning, social functioning, role-functioning emotional, role-functioning physical, vitality, bodily pain, mental health and general health perceptions. These dimensions are then used to compute a physical component score (PCS) and a mental component score (MCS) for each hemodialysis patient. A 1-point increase in PCS is independently associated with a 2% reduction of the mortality rate and odds of hospitalization, the same being true for MCS as mortality predictor (6). Furthermore, PCS emerged as a better predictor of mortality than some of the more "classical" indices – such as dialysis adequacy (Kt/V) (7).

Factors that potentially influence hemodialysis patients' QoL and the evolution of QoL scores over time are therefore of paramount importance. Any nephrologist should aim in his therapeutic goals not only to simply improve survival but also QoL. A vast number of studies focused on identifying variables which might affect the quality of life of dialysis patients (8). There are mainly three types of such variables: socio-demographic variables (age, gender, socioeconomic status and educational level), clinical variables (early referral to nephrologist, hemoglobin, Kt/V, serum albumin) and comorbid conditions. In addition, in many chronic diseases (9-11), a psychological variable – patients' personal representations of illness – also predicts the QoL. Recently, our group (12) confirmed such an important impact of patients' illness representations for a well-dialyzed population. In particular, the perception of the disease as having a chronic course, the personal control and the emotional response to the disease emerged as powerful predictors of QoL

in ESRD patients, explaining up to 36% of the variance in the SF-36 scores (12). Similar results were subsequently obtained by Pascalides et al in a type-2 diabetes population (13).

There are few longitudinal studies assessing changes in hemodialysis patients' QoL, their determinants and potential relevance. Most importantly, there is no longitudinal study evaluating changes in illness representations and their impact on changes in QoL at the same time in the same HD population. Therefore, the main objective of our study was to describe for the first time in a group of well-dialysed patients the dynamics of both quality of life and illness representations over a significantly long follow-up period and to investigate the relationship between these two dynamics. We aimed to assess if baseline illness representations might explain subsequent changes in QoL scores over time and what is the extent of their impact when controlling for clinical variables and baseline QoL scores. ❑

SUBJECTS AND METHODS

This is a longitudinal study, in which a baseline cohort was reinvestigated after a 2-year follow-up period, using the same instruments. During the follow-up period, hemodialysis treatment was prescribed according to European Best Practice Guidelines (14).

Study population

Eighty-one clinically stable, well-dialyzed HD patients (minimum 5 hours/ session, 3 times/ week effective dialysis time, Qb = 350 mls/min, Qd = 600 mls/min, F60 dialyzers, conductivity = 135 mS, target monthly eKt/V ^{3} 1,2; all other dialysis targets were set as per European Best Practice Guidelines (14)) from the Dialysis and Renal Transplantation Center, University Hospital "Dr. C. I. Parhon" Iasi, Romania, completed at baseline and after 2 years the assessment questionnaires for health-related quality of life and illness representations (see below). Exclusion criteria and characteristics of the baseline cohort have been presented elsewhere (12). There were 82 patients included in the study. During the follow-up period one patient received a renal transplant (female, 42 years old). No patient died during the study period. For the remaining 81 patients the response rate to the questionnaires at follow-up was 100%. This high rate is explained by

the fact that unlike most of the European countries, where the psychologist has only the role of a consulting specialist, in Romania the psychologist is part of the dialysis staff and a permanent presence in the dialysis center' treatment process.

The study was approved by the University Hospital's Ethical Committee and was performed in agreement with the Helsinki declaration of human rights.

Biochemical and clinical assessment

The values for hemoglobin, phosphorus, parathormone (PTH) and Kt/V at baseline and follow-up were recorded for each hemodialysis patient. Changes in these variables were used in the multiple regression analysis as potential predictors for the change in QoL scores at follow-up.

Significant events during the two years were also recorded. Five patients were hospitalized for vascular access problems, two for gastroduodenal ulcer and two for de novo angor pectoris.

The Short Form Health Survey Questionnaire

(SF-36) adapted for Romanian population (15) – was used to assess 8 dimensions of QoL: physical functioning, social functioning, role-functioning emotional, role-functioning physical, vitality, bodily pain, mental health, and general health perceptions. Two summary scores were obtained: one for the **physical component** (assessing the physical functioning – PF, role-functioning physical – RF, vitality – VT, bodily pain – BP, and general health perceptions – GH) and one for the **mental component** (assessing the social functioning – SF, role-functioning emotional – RE, mental health – MH, vitality – VT, and general health perceptions – GH). Scores range from 0 to 100, a higher score indicating a better QoL.

Illness representations were assessed by a structured interview containing questions derived from *The Revised Illness Perception Questionnaire* (16), a recently developed, well-validated and widely used quantitative measure of the five components of illness representations in Leventhal's self-regulatory model (17). This instrument had been successful in predicting different aspects of adaptation and recovery in various chronic illnesses. The following six components of illness representations were

evaluated: time-line, consequences, personal control, treatment control, coherence and emotional response (see below for details). The patients rated the items on a 4-point scale, ranging from "strongly disagree" to "strongly agree". The reliability scores (Chronbach's alpha) for the six components of illness representation at baseline and follow-up were comparable to those found in other studies assessing dimensions of illness representations (data not shown) (10,11).

The *time-line* dimension was assessed by 6 items (a=.62 at baseline and 0.64 at follow-up); e.g. "I expect to have this illness for the rest of my life". A higher score on this dimension indicates the perception of a chronic course of the disease.

The *consequences* dimension was assessed by 6 items (a=.64 at baseline and 0.61 at follow-up), a higher score indicating that the patient considered his disease as having serious consequences upon his life (e.g. "My illness strongly affects the way others see me").

Personal control dimension comprised 5 items (a=.70 at baseline and 0.67 at follow-up) – e.g. "My actions will have no effect on the outcome of my illness". In this case, a higher score indicates the perception of a better personal control upon disease.

Treatment control was assessed by 5 items (a=.68 at baseline and 0.69 at follow-up), a higher score indicating that the patient considers hemodialysis efficient in controlling end-stage renal disease (e.g. "There is nothing which can help my condition.")

Coherence is a measure of how well the patient understands his illness. It was evaluated by 5 items (a=.63 at baseline and 0.62 at follow-up), a higher score on this dimension indicating that patient considers to understand end-stage renal disease (e.g. "My illness doesn't make any sense to me").

The last dimension assessed – *emotional response* – had 6 items (a=.74 at baseline and 0.71 at follow-up), a higher score on this dimension indicates a more intense emotional reaction to the disease (anxiety, depression); e.g. "My illness makes me feel angry."

Statistical analysis was performed using SPSS 11.0 for Windows. Cross-sectional correlation analysis at baseline and follow-up was performed using Spearman's rho. A paired t test was used to compare follow-up *vs* baseline data. A multivariate regression analysis (stepwise

method) was used to identify predictors of change in QoL scores at 2 years follow-up. The illness representations from baseline were entered in the regression model at step 1, at step 2 we included all potentially relevant clinical variables while at step 3 we included baseline QoL scores (PCS and MCS). A p value of 0.05 or less was considered to indicate statistical significance.

	Baseline	Follow-up
Dialysis vintage (mean months)	72	97.2
Prevalence LVH (% patients)	65.7	66.4
Mean number of antihypertensives	2.2±0.9	2.3±0.8
Hemoglobin (g/dL)	11.3 ± 1.2	10.9 ± 1.09
Kt/V	1.41 ± 0.5	1.42 ± 0.54
Phosphate (mmol/L)	1.9 ± 0.24	1.8 ± 0.26
PTH (pg/ml)	558 ± 488.6	584 ± 460.2

TABLE 1. Biochemical data at baseline and 2 years follow-up (N = 81, mean age = 47.9, 55.5% males, 13.6% diabetes)

Legend: LVH = left ventricular hypertrophy

RESULTS

Biochemical data at baseline and follow-up are shown in Table 1.

Quality of life data. The study population MOS SF-36 summary scores at baseline and follow-up, compared to the reference Romanian general population (18) and a similar Romanian HD population (15) are presented in Table 2. Overall QoL scores improved over the 2 years-period in our population. PCS improved from 46 to 52.8 (p<0.01) while a non-significant positive trend was observed for MCS (from 51.3 to 54.4, p=ns). Several individual dimensions of QoL significantly improved over the 2-years study period in both PCS and MCS scores: physical function, role-physical, general health and mental health (Figure 1).

Summary scores	Study sample		Reference Romanian population	
	Baseline Mean (SD)	Follow-up Mean (SD)	Age-matched HD population (15) Mean (SD)	General population (18) Mean (SD)
PCS	46.1 (12.05)	52.8 (19.53) *	44.8 (16.9)	64.4 (21.1)
MCS	51.3 (20.02)	54.4 (22.5)	51.5 (19.3)	63.8 (23.5)

TABLE 2. Study population SF-36 summary scores (PCS and MCS) - baseline and follow-up data compared with reference populations [data from Ursea et al (15) and Mihaila et al (18)]

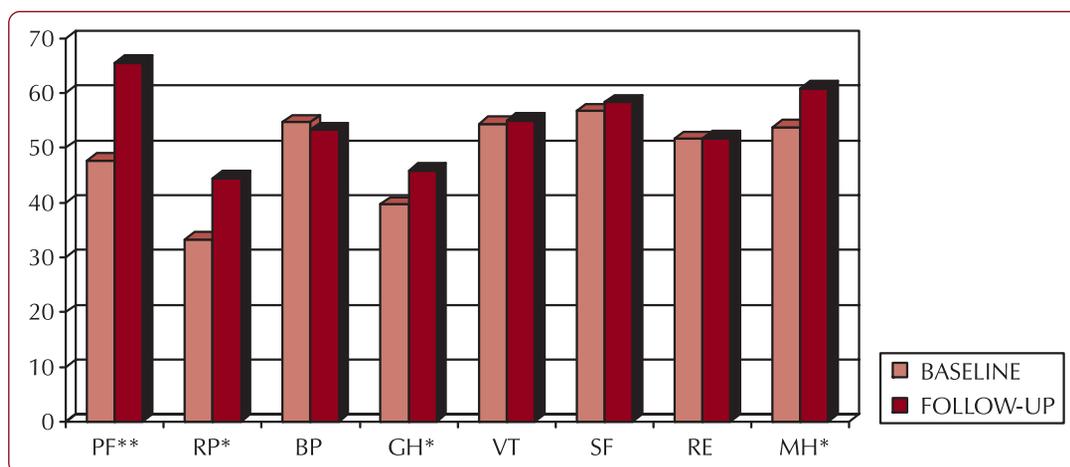Legend: PCS = physical component summary score, MCS = mental component summary score.
* p = 0.01

FIGURE 1. Comparison of individual quality of life component scores of hemodialysis patients – baseline vs follow-up

Legend: PF = physical functioning, SF = social functioning, RE = role-functioning emotional, RP = role-functioning physical, VT = vitality, BP = bodily pain, MH = mental health, GH = general health perceptions
*p<0.05, ** p<0.001

Illness representations scores for the six dimensions assessed at baseline and follow-up are presented in Table 3. At baseline, the high scores obtained by our patients for all 6 dimensions indicate that they perceive their illness as having a chronic course (time line), they understand it quite well (coherence) and consider that it can be influenced by their own actions (personal control) and by treatment. However, at the same time, the perceived negative consequences of the disease upon their lives are considerable (consequences), as is their emotional response. When investigating the dynamics of illness representations dimensions, we observed that at follow-up patients' perception is better in 3 out of the 6 dimensions evaluated: understanding of the illness (p=0.003), treatment control (p=0.02) and the emotional reaction to the disease (p=0.002).

Important information regarding illness representations may be derived from analysis of the relationship between individual components at follow-up (Table 4). The treatment control dimension is positively associated with coherence and personal control and, as expected, negatively with consequences and emotional response (p<0.01), suggesting that dialysis is considered a more efficient treatment, that there is a better understanding of illness, a higher perceived personal control and lesser perceived consequences of the illness upon personal lives.

Relationship between QoL and illness representations. At follow-up (see Table 5) only the personal beliefs about illness' duration were not associated with PCS and MCS (*versus* only 2 out of 6 dimensions for PCS and 3 out of 6 dimensions for MCS at baseline, p<0.05). Furthermore, all the dimensions of illness representations correlated stronger than at baseline, with quality of life.

Multivariate regression analyses were computed to evaluate the change in scores observed for both PCS (delta PCS) and MCS (delta MCS), after 2 years of follow-up – see Table 6. Even after adjusting for baseline QoL status and changes in biochemical parameters, the dynamics in QoL over the 2 years follow-up period are predicted by baseline illness representations. The final model explains > 80% of the variance in DPCS and DMCS. Of note, the baseline emotional response, personal control and coherence account for 51% of the variance in DPCS, while a single dimension – disease consequences – accounts for 39% of the variance in DMCS.

	Baseline Mean ± SD (median)	Follow-up Mean ± SD (median)	p
Coherence	2.6±0.6 (2.6)	2.8±0.6 (2.6)	0.003
Consequences	2.9±0.2 (3.0)	2.9±0.5 (3.0)	ns
Emotional response	2.7±0.8 (2.6)	2.4±0.7 (2.5)	0.002
Personal control	3.0±0.2 (3)	2.9±0.4 (2.8)	ns
Treatment control	2.6±0.5 (2.6)	2.7±0.4 (2.8)	0.02
Time-line	3.3±0.4 (3.1)	3.1±0.4 (3.0)	ns

TABLE 3. Comparison between illness representations dimensions – baseline vs follow-up (see *Methods*)

	Coherence	Consequences	Emotional response	Personal control
Consequences	-0.85**			
Emotional response	-0.73**	0.84**		
Personal control	0.22*	ns	-0.28*	
Treatment control	0.69**	-0.57**	-0.78**	0.48**
Treatment duration	ns	0.53**	0.25*	0.53**

TABLE 4. Correlations between illness representations dimensions (follow-up)

* p < 0.05, **p < 0.01

		Coherence	Consequences	Emotional response	Personal control	Treatment control	Time line
PCS	Baseline	ns	ns	-0.42**	ns	ns	0.42**
	Follow-up	0.4**	-0.5**	-0.6**	0.34**	0.65**	ns
MCS	Baseline	0.5**	ns	-0.54**	0.26*	ns	ns
	Follow-up	0.7**	-0.82**	-0.81**	0.23*	0.7**	ns

TABLE 5. Correlations between quality of life component scores (PCS and MCS) and illness representations dimensions in hemodialysis patients (baseline and follow-up)

Legend: PCS = physical component score; MCS = mental component score
* p < 0.05, **p < 0.01

	ΔPCS		ΔMCS	
	β	Cumulative R2	β	Cumulative R2
Baseline IR (step 1)		*0.51*		*0.39*
Personal control	0.22*		0.17	
Emotional response	-0.7*		-0.25	
Coherence	0.11*		0.41	
Consequences	0.23		-0.5*	
Clinical variables (step 2)		*0.63*		*0.58*
ΔHb	0.48*		0.55*	
ΔKt/V	0.68*		0.58*	
Baseline QoL (step 3)		*0.87*		*0.82*
PCS	-0.7*		-0.8*	
MCS	0.82*		0.61*	

TABLE 6. Multivariate regression analysis for change in quality of life scores (DPCS and DMCS) during the 2 years follow-up period

IR = illness representations
* p < 0.001

DISCUSSIONS

The aim of the present investigation was to describe, for the first time in a longitudinal study, the dynamics of QoL and individual's illness representations. This approach complements and further refines the recently described major role of patients' illness representations as a determinant of QoL of HD patients, derived from a cross-sectional analysis (12). Our results indicate a relatively low QoL at baseline, but similar to other national data reported in comparable HD populations (15). While still lower than the quality of life observed in the general population, at follow-up, both the PCS and MCS scores of our patients significantly improved. At the same time, there was a significant improvement in illness perceptions: after 2 years HD patients considered to better understand their illness, had fewer negative emotional reactions and considered dialysis as more efficient (than at baseline), in controlling

their illness. Followed longitudinally, the relationships between QoL and illness representations demonstrate that better physical scores are obtained by patients with a lower emotional response to the disease, while better mental scores are obtained by those patients who considered to better understand their illness.

Few studies assessed prospectively changes in QoL, in HD patients. In particular, one study (19) with incident patients followed over an 18-months period showed that only physical scores of SF-36 improved over time, while mental scores remained unchanged. This was subsequently confirmed in incident patient populations (20), in contrasts to reports from prevalent populations, with significant comorbidities, where QoL proved to be stable over time (21). It is therefore possible that, the absence of significant comorbidities – an important characteristic of our population, might have positively influenced QoL scores. Clearly, significant comorbidities will have a major

impact on QoL, obscuring an independent and significant role of the dialysis procedure.

A change in patients' perceptions was observed over time; illness representations are significantly better at follow-up for coherence, emotional response and treatment control. Thus, following a 2-year period, our patients have fewer negative emotional reactions to the disease, a better understanding and perception that dialysis is more efficient in controlling their illness. Significant changes in chronic patients' perceptions regarding illness and treatment are demonstrated by other prospective studies, in non-renal populations. One recent study in 2745 patients with coronary heart disease (CHD) deserves particular attention (22). At 1 year follow-up CHD patients reported more negative consequences of the illness upon their lives and perceptions of a greater symptom impact as assessed by *Illness Perception Questionnaire (IPQ)* (23). Also, the beliefs related to personal control of illness decreased significantly. These changes were best explained by baseline illness perceptions, accounting for 12-30% of scores' variance (22). Another recent study, using also the *IPQ*, this time in women treated for breast cancer (24), also described at 1 year of follow-up a greater symptom impact and a shorter perceived duration of illness (time-line). The latter is speculated to imply pessimism about survival at 1 year after breast-cancer surgery.

Illness representations differ across different diseases (23,25,26), so that a specific pattern of identity, time-line, causes, consequences and control exists for every disease. Furthermore, this pattern may change differently in time for every disease and should be described for further reference. Our study is the first to describe changes in illness perceptions in a large HD population. Our findings suggest that the changes in illness perceptions are influenced by patient's characteristics and by disease's characteristics at the same time.

According to Leventhal et al (27) the illness representations dimensions are interrelated, functioning as groups of beliefs instead of single cognitions. We confirm this statement for ESRD patients on hemodialysis, demonstrating significant correlations between some of the six components of illness representations assessed at baseline. Moreover, at follow-up all six dimensions of illness representations evaluated are significantly interrelated. In our population, the more the patients consider to understand their illness, the better is their personal and treatment control and the less the perceived

consequences of the disease and the negative emotional reactions to the disease.

The cross-sectional relationship between QoL and illness representations in chronic illness populations including ESRD is already established (9-11,28). The emotional response and personal control are major predictors of QoL in patients with chronic fatigue syndrome, Addison's disease and multiple sclerosis (10, 11,28). Similarly, in diabetic patients, understanding the nature of the diabetic disease and a superior perceived control of diabetes emerged as significant predictors of engagement in diabetes-specific health behaviors and positive perceptions of QoL (9). Finally, in HD patients the chronicity perception (see above), the personal control and the emotional response have the potential to be powerful predictors of QoL. All these findings suggest a common mechanism of adaptation to chronic illnesses (29).

This is the first longitudinal study which includes illness representations held by chronic renal patients as a potential contributor to changes in QoL as assessed with SF-36. All previous studies that prospectively investigated QoL of HD patients relied solely on clinical parameters as potential determinants. Our results show that patients' illness representations not only predict QoL scores at one particular moment but also represent the most important predictors of QoL scores over time. This suggests that when treating chronic HD patients we should routinely address the importance of patients' emotions, the potential impact of the disease on their lives and increase by means of professional advice their understanding and sense of control over the illness. Our data are at the same time in line with previous studies, showing that improvements in PCS / MCS scores are seen in patients with better anemia control and dialysis adequacy (8).

One limitation of our study concerns the relatively small number of patients and the characteristics of the HD population included in this analysis: prevalent and well-dialysed, with no significant baseline comorbidities. Furthermore, the option of renal transplantation as a renal replacement therapy is reduced in Romania. This explains why, except with one patient, all the other patients were available at follow-up. Therefore it is necessary to confirm our findings in incident dialysis patients with a higher co-morbidity burden. Second, our study was not designed to dissect the causality of the

relationship between QoL and illness representations observed in our study, both at baseline and at follow-up. This can be twofold: it can be that a better QoL influences patient' illness representations or that the QoL depends on these representations. Further studies should address this relationship.

In conclusion, illness representations improve over time. In addition to biochemical data, evaluation of illness representations held by HD patients is absolutely mandatory when assessing patients' quality of life. Furthermore, without knowing patients' personal models of illness, the assessment of QoL scores in prospective/longitudinal studies remains an act of comparing numbers not patients.

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