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Original Article

A simple risk score predicts poor quality of life and non-survival at 1 year follow-up in dialysis patients

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Abstract

Background. Quality of life (QoL) in end-stage renal disease patients has become an important focus of attention in evaluating dialysis. We studied risk factors of poor QoL at 1 year follow-up.

Methods. Of a baseline sample of 80 dialysis patients, we contacted 60 patients who were alive at 1 year follow-up. QoL data were obtained for 46 (76.7%) of these patients. QoL measured with the SF-36 [physical health component score (PCS) and mental health component score (MCS)] at 1 year-follow-up was predicted by means of multivariate regression analysis by data collected at baseline using INTERMED—an observer-rated method to assess biopsychosocial care needs—and several indicators for disease severity and comorbidity.

Results. The regression models explained 32% of the variance in PCS and 40% in MCS. INTERMED score ($P < 0.01$) was the only independent risk factor for low MCS, while for low PCS, diabetic comorbidity ($P = 0.02$) and age ($P = 0.03$) were independent risk factors. A simple risk score consisting of INTERMED ≥ 21, diabetic comorbidity and age ≥ 65 was significantly correlated with non-survival ($P = 0.02$) and with PCS ($P < 0.01$) and MCS ($P < 0.01$) in surviving patients, although not with hospital admissions during follow-up.

Conclusions. A simple risk score based on INTERMED, age (≥ 65) and comorbid diabetes (yes/no) can be used to detect patients at risk of poor QoL and non-survival at an early stage of treatment.

Keywords: dialysis; end-stage renal disease; INTERMED; quality of life; SF-36

Introduction

Quality of life (QoL) in end-stage renal disease (ESRD) patients is threatened by multiple biological and psychosocial stresses and has therefore become a focus of attention in evaluating dialysis [1–3]. ESRD patients experience severe disruptions of lifestyle, such as limitations in physical activity and social life, and many will encounter difficulties in coping with their disease and the uncertainty of their future [3,4]. Several studies have reported limited QoL in both haemodialysis [5] and peritoneal dialysis patients [1,6]. Also, depression is a common psychiatric complication in ESRD patients, with a strong impact on QoL [3]. Moreover, a complex interaction between depression, QoL, compliance and survival is observed in this high-risk population [3,7,8].

The SF-36 has been established as the most suitable instrument to measure QoL in dialysis patients [9–11], focusing both on physical and mental health. The SF-36 is a patient-rated instrument that includes assessment of physical function, social function, limitations in role due to physical health, limitation in role due to mental health, vitality, bodily pain and general health. Two sum scores can be calculated: a physical component summary score (PCS) and a mental component summary score (MCS) [10]. It was found that prospective hospitalizations correlated significantly with SF-36 and that low SF-36 scores—particularly MCS—resulted in significantly higher risk of death within the following 12 months [9].

During recent years, INTERMED has been developed as a screening instrument to identify patients with multiple care needs and is based on the concept of case complexity [12–14]. Case complexity is determined by diagnosis [15] as well as by a variety of other parameters that influence patient management and prognosis, such as chronicity and severity of illness, limitations in daily functioning, psychiatric comorbidity and social vulnerability. Several studies have supported the psychometric quality of INTERMED

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in terms of its reliability and validity. Both in ambulatory populations and in in-patients, INTERMED identified patients with increased healthcare use, poor QoL or a diminished response to medical treatment. INTERMED provides a quick overview of the patient's vulnerabilities that can be used to formulate an integrated treatment plan. The goal of the present study was to predict QoL at 12 months follow-up in surviving dialysis patients by using INTERMED. If INTERMED is related to poor QoL at follow-up, it could be used to detect patients at risk of poor QoL.

Subjects and methods

Procedure

After informed consent, a medical student (G.M.F.R.) interviewed the patients and scored the INTERMED, based on this interview and a review of the medical chart. After ~1 year (median follow-up: 16 months; range: 13–16 months), surviving patients were invited to complete a QoL follow-up assessment by mail. Patients who did not return the questionnaire were contacted 2 months later and asked to complete the QoL assessment by telephone.

Sample

The baseline sample consisted of patients ($n = 80$) treated at the nephrology outpatient unit of the VU Medical Center in Amsterdam during the baseline period (November–December 1999). After 12 months, the 60 surviving patients were contacted for follow-up QoL assessment with SF-36 by means of a letter. Fifteen patients returned the SF-36 spontaneously and 32 patients participated in an interview at their next visit to the nephrology outpatient unit; however, one patient stopped in the middle of the interview, resulting in complete follow-up data for 46 of the 60 surviving patients (76.7%). Patients refusing the follow-up assessment were compared with patients who completed follow-up assessment on baseline variables in order to study whether refusal was non-random. We found no differences in age, disease/treatment characteristics (type of dialysis, renal function, comorbidity and time on dialysis), biological parameters [serum albumin, parathyroid hormone (PTH), phosphate, ultrafiltration, normalized protein catabolic rate and Kt/V] and INTERMED. There were more women among the patients refusing the follow-up assessment (10/14 *vs* 27/66; $P = 0.04$).

Variables

At baseline, the following variables were recorded: demographics (sex and age), disease/treatment characteristics (type of dialysis, renal function, comorbidity and time on dialysis) and biological parameters (serum albumin, PTH, phosphate, ultrafiltration, normalized protein catabolic rate and Kt/V area).

INTERMED

INTERMED is an observer-rated instrument that classifies information from a structured medical history-taking into four domains (biological, psychological, social and healthcare) and leads to a score that indicates the patient's level of care needs. The INTERMED interview takes ~20 min to score. Domains are assessed in the context of time (history, current state and prognosis), resulting in 20 variables that are scored as 0–3. All variables are rated according to a manual, with anchor points describing the spectrum of no vulnerability (0) to serious vulnerability (3). The INTERMED total score is obtained by adding the individual variables (range: 0–60). In correspondence with previous work, a cut-off point of 20/21 was used to indicate complex care needs. The INTERMED was administered at baseline. In Figure 1 an example of an INTERMED assessment is presented together with the formulation of a management plan, in order to show how care needs are visualized in this assessment system.

SF-36

The SF-36 consists of 36 patient-rated items, organized into eight scales [16]. The number of response choices per item ranges from two to six. Each of the scales is recoded into standardized scores, which are subsequently used to construct a PCS and a MCS, based on the factors found by Hays and Stewart [17]. Scores were transformed so that a score of 50 (SD = 10) indicates functioning comparable to the general population and lower scores indicate poorer functioning. When scores on one or two of the scales were missing, the median score of the sample was inserted. We used the Dutch version of the SF-36, which has been developed and validated in the International Quality of Life Assessment Project [18]. The SF-36 was rated at follow-up.

Data analysis

The first goal of this study was to assess the possibility to predict QoL by a series of baseline characteristics, of which we hypothesized INTERMED to have a specific importance. The second goal, if QoL is predictable, was to determine whether a simple risk score can be constructed, which could be used to detect patients at risk of a poor prognosis in terms of QoL, non-survival and prospective hospital admissions.

Based on their INTERMED scores, patients were divided into those having low (INTERMED <21) or high (INTERMED ≥ 21) scores and were compared on baseline data: disease characteristics, biological parameters and sociodemographics. Multivariate linear regression models were constructed to predict SF-36 PCS and MCS by baseline variables. We used multiple linear regression analysis, since both scales had approximately normal distributions. In order to balance the number of independent variables to the number of patients, we selected only the baseline variables (sociodemographics, disease characteristics, biological parameters and INTERMED) that were significantly correlated with the outcomes. For these analyses, we used Spearman rank correlations (continuous variables with continuous variables) and the Mann–Whitney *U*-test (categorical variables with categorical variables). The significant variables were forced into a model to predict PCS and MCS. Of the significant variables in the multivariate model, a simple risk score was developed, which was correlated with QoL at follow-up, survival status and prospective hospital admission (nephrology-related and other). A sensitivity analysis was conducted in which non-survival was recoded as a QoL score of 0. We added this analysis in order to model attrition due to

Case vignette: A 27-year-old lady was admitted through the dialysis unit on the department of nephrology for the evaluation of diarrhoea, which has now lasted for about half a year. On the second day of admission the following information was obtained from the medical chart and the structured INTERMED patient interview conducted by the nurse. There were several reasons for the admission; first although extensive diagnostic evaluations have been performed and an enteritis regionalis or a SLE-related phenomenon was most feasible, the definite diagnosis was still to be determined. Therefore a laparascopy was considered. Second patient's condition declined as she has lost about 10 kilo's in the last month. Third the patient had informed her doctor that she is almost incapable of doing anything at home. She is known for systemic lupus erythematosis (SLE) since 5 years and is treated by a nephrologist, as her kidneys are the primary location of the disease. It had taken quite some time and several referrals to get her kidney disease diagnosed as being part of SLE. There has been a gradual decline of the kidney function to end stage renal disease (ESRD) and since two years patient is haemodialysis-dependent (2 times a week). Patient is living with her husband. Their relation is complicated by the fact that she always feels ill and that she is not able to get children. It resulted in negative self-esteem, quarrels and fights. Due to the illness patient has never been able to work but did some voluntary work. Patient is shy and not assertive, and has negative feelings about herself. Sometime ago she tried to commit suicide with medication when she realized she would not be able to have children. During the last years she had felt most of the time a little blue and was able to perform the way she used too. As a result of the new emerging symptoms (diarrhoea) she confesses that she really feels depressed. Basically patient is compliant though there is some resistance due to the side effects of the medication (prednison). Also, during the last weeks, she has missed medication and an appointment for dialyses.

The following INTERMED score was obtained (total score =37):

	HISTORY	CURRENT STATE	PROGNOSES
Biological	3 Chronicity 2 Diagnostic dilemma	2 Severity of symptoms 2 Diagnostic challenge	2 Complications and life threat
Psychological	3 Restrictions in coping 1 Psychiatric dysfunctioning	1 Resistance to treatment 2 Psychiatric symptoms	3 Mental health threat
Social	3 Restrictions in integration 1 Social dysfunctioning	0 Residential instability 3 Restrictions of network	2 Social vulnerability
Health Care	2 Intensity of treatment 1 Treatment experience	1 Organisation of care 0 Appropriateness of referral	3 Coordination

Management plan: During admission, a further diagnostic evaluation would be required. If possible, symptomatic therapy should be started quickly to counteract the debilitating effects of the diarrhoea. The status of dialysis would also need evaluation. The patient should be seen by a psychiatric consultant to confirm the diagnosis of depression, to assess and handle the suicide risk, to further detail the reasons for non-compliance and to indicate the need for a pharmacological treatment. Based on the high INTERMED score it was decided that a multidisciplinary case-conference was necessary as soon as the psychiatric consult was effectuated and the framework of the further diagnostic work-up of the diarrhoea and its treatment was defined. To counteract the ambivalence towards treatment caused by the earlier experiences and the current depression, her current physical problems were communicated clearly with the patient and her partner. During hospitalization, a coordinator of care was assigned to monitor and adjust the process of care, as well as to instruct the staff in the psychological approach of the patient.

Fig. 1. Example of an INTERMED assessment and management plan.

non-survival, following the logic of Quality-adjusted Life Years (QALY) in which non-survival is also coded as having a QoL score of 0 [19].

Results

Tables 1 and 2 summarize the background characteristics of the baseline sample and the patients that were still alive at 12 months follow-up. About half of the patients were treated with haemodialysis, 31% with continuous ambulatory peritoneal dialysis (CAPD) and 19% with continuous cycling peritoneal dialysis (CCPD). About one-fifth of the patients suffered from a cardiovascular disease and one-fifth had diabetes mellitus as a comorbid condition. Half of the patients did not have residual clearance or diuresis.

The median INTERMED score was 19 (P10–P90: 11–27). Dividing the population into two groups (low and high INTERMED scores) did not result in

significant baseline differences with respect to type of dialysis, comorbidity and biological factors (Tables 3 and 4). Patients with a high INTERMED score, however, were on more types of medication than patients with low INTERMED scores ($P = 0.01$).

We found a mean PCS of 38.2 (SD = 9.7) and MCS of 48.7 (SD = 9.8) at follow-up, which is highly comparable to findings presented elsewhere [10]: 36.9 (8.8) and 48.7 (9.3), respectively. Also comparable with reports elsewhere in the literature, we found a negative association of PCS with age ($R = -0.38$; $P = 0.01$) and not between MCS and age ($R = -0.05$; $P = 0.75$). We found no sex differences in PCS and MCS. The INTERMED score was significantly associated with MCS ($R = -0.56$; $P < 0.01$) but not with PCS ($R = -0.21$; $P = 0.17$).

Table 1. Characteristics of the baseline patients ($n = 80$) and surviving patients ($n = 60$)

	Baseline patients		Surviving patients	
	n	%	*n*	%
Sex				
Male	43	53.8	30	50.0
Female	37	46.3	30	50.0
Age (years)				
18–40	18	22.5	17	28.3
41–64	30	37.5	24	40.0
≥65	32	40.0	19	31.7
Type of dialysis				
HD	40	50	29	48.3
CAPD	25	31.3	16	26.7
CCPD	15	18.8	15	25.0
Comorbidity				
Cardiovascular disease	19	24.1	12	20.0
Diabetes mellitus	18	22.5	11	18.3
Renal function				
Diuresis	39	48.8	31	51.7
Residual clearance	33	46.5	29	48.3

Prediction of QoL

Seven of the baseline variables had significantly negative associations with PCS or MCS in bivariate analyses: age, diabetic comorbidity, number of types of medication, INTERMED, haemodialysis as treatment, PTH and Kt/V urea. Fitting these seven baseline variables in linear regression models resulted in 40.4% explained variance for MCS (multiple $R = 0.635$; R^2 adjusted = 0.294) and 31.7% explained variance for PCS (multiple $R = 0.563$; R^2 adjusted = 0.191). In Table 5 the regression weights and significance levels of the individual predictors are shown.

Having diabetes as a comorbid condition is associated with a decrease in PCS of 10 points (= 1 SD), while each age year is associated with a decrease in PCS of 0.2 points. INTERMED is the only independent predictor of MCS and each increase in INTERMED score is associated with almost one point decrease in MCS. Leaving out INTERMED from the regression models resulted in a reduction of explained variance for PCS of 4% (from 32% to 28%) and for MCS of 16% (from 40% to 24%). Moreover, the regression model of MCS

Table 3. Comparison of low and high INTERMED total scores using the χ^2 statistic for comparison of categorical data

	INTERMED score		χ^2	*P*-value
	<21 *n* = 45	≥21 *n* = 35		
Type of dialysis (*n*)				
HD	22	18	0.87	0.65
CAPD	13	12		
CCPD	10	5		
Comorbidity (*n*)				
Diabetes mellitus	7	10	1.85	0.17
Cardiovascular	11	8	0.01	0.93

Table 2. Characteristics of the baseline patients ($n = 80$) and surviving patients ($n = 60$)

	Baseline patients		Surviving patients	
	Median	P10–P90	Median	P10–P90
INTERMED (total)	19	11–27	18.5	11–25
Biological parameters				
Serum albumin (g/l)	32	25–37	33	25.9–38
PTH (pmol/l)	12	2.74–53.3	12.5	2.18–54.3
Phosphate (mmol/l)	1.73	1.09–2.29	1.71	1.08–2.31
Ultrafiltration (ml/session)				
HD	2950	450–4580	3000	400–4520
CAPD	1150	320–2000	1125	180–1850
CCPD	900	375–1750	900	375–1750
NPCR (g/kg/day)	0.98	0.51–1.33	1.00	0.52–1.33
Kt/V urea (weekly)				
HD	2.8	1.2–4.3	3.4	2.11–4.47
CAPD	2.2	1.6–3.4	2.3	1.77–3.40
CCPD	2.2	1.3–4.1	2.3	1.33–4.11
Time on dialysis (months)	26.5	3–84.5	27	4.7–84.5
Medications (number)	9	5–14	9	4–14

NPCR, normalized protein catabolic rate.

Table 4. Comparison of low and high INTERMED total scores using the Mann–Whitney *U*-test for comparison of continuous data

	INTERMED score		*Z*-value	*P*-value
	<21 $n=45$	≥21 $n=35$		
Medications[a]	8	10	−2.58	0.01
Age (years)	58	59	−0.70	0.49
Diuresis	0	0	−0.699	0.49
Residual clearance	0.17	0	−1.426	0.15
Serum albumin (g/l)	32	32	−0.229	0.82
Months on dialysis	24	27	−0.439	0.66
PTH (pmol/l)	10	14	−1.77	0.08
Phosphate (mmol/l)	1.75	1.72	−0.24	0.98
Ultrafiltration (ml/session)				
HD	3000	2650	−0.4	0.70
CAPD	1200	1125	−0.11	0.91
CCPD	875	900	−0.49	0.62
NPCR (g/kg/day)	1.01	0.93	−1.582	0.11
Kt/V urea (weekly)				
HD	2.6	2.8	−0.95	0.35
CAPD	2.3	2.2	−1.1	0.26
CCPD	2.2	2.1	−0.19	0.85

The values presented are median scores. [a]Number of different types of medication. NPCR, normalized protein catabolic rate.

did not reach overall statistical significance when excluding INTERMED from the model.

Construction of a risk score

Based on the regression models, a simple risk score was constructed: having diabetes, 1 point; age ≥65 years, 1 point; and INTERMED score >20, 1 point. In Table 6 the association between the risk score, survival, hospital admissions and QoL is shown.

In the baseline sample of 80 patients, the risk score is significantly associated with survival ($P=0.02$): while of the patients with a low score (0) only 8% had died during the 1 year follow-up, 42% of the patients with a high risk score (2–3) did not survive. In the surviving patients, the risk score was associated with both PCS ($P<0.01$) and MCS ($P<0.01$), but not with the number of hospital admissions during the 1 year follow-up.

Additional analysis

We performed an additional analysis in which non-survival at follow-up was recoded as zero on both

Table 5. Regression model of SF-36 PCS and MCS[a]

	SF-36 PCS				SF-36 MCS			
	B	SE	T	*P*-value	B	SE	T	*P*-value
Diabetes[b]	−10.12	4.3	−2.4	0.02	−0.74	4.0	−0.5	0.64
INTERMED	−0.4	0.3	−1.4	0.18	−0.9	0.3	−3.3	<0.01
Age	−0.2	0.1	−2.2	0.03	−0.04	0.09	−0.2	0.86
Medications[c]	0.5	0.4	1.3	0.20	−0.2	0.4	−0.5	0.62
Haemodialysis[b]	2.3	3.7	0.6	0.55	−1.8	3.5	−0.5	0.61
PTH	−0.03	0.06	−0.4	0.68	−0.03	0.06	−0.6	0.58
Kt/V	−0.8	2.1	−0.4	0.71	−1.8	2.0	−0.9	0.36

[a]PCS: multiple $R=0.563$, $R^2=0.317$, R^2 adjusted $=0.191$; MCS: multiple $R=0.635$; $R^2=0.404$; R^2 adjusted $=0.294$.
[b]Dummy variable: yes = 1; no = 0.
[c]Number of different types of medication.

Table 6. Comparison of low-risk and high-risk patients for QoL, survival and nephrological-related hospital admissions

	Low risk (risk score = 0)	Moderate risk (risk score = 1)	High risk (risk score ≥2)	Test statistic	*P*-value
Baseline sample	24	30	26		
Survival (*n*, %)	22 (92%)	23 (77%)	15 (58%)	$\chi^2=7.8$[a]	0.02
Non-survival (*n*, %)	2 (8%)	7 (23%)	11 (42%)		
Surviving patients	22	23	15		
PCS (mean, SD) ($n=46$)	42.8 (9.1)	36.4 (9.8)	34.0 (8.2)	$\chi^2=5.9$[b]	0.05
MCS (mean, SD) ($n=46$)	54.9 (4.7)	46.2 (10.8)	43.4 (9.4)	$\chi^2=10.4$[b]	<0.01
Nephrology-related admissions					
No (*n*, %)	3 (14%)	7 (30%)	4 (27%)	$\chi^2=1.9$[a]	0.39
Yes (*n*, %)	19 (86%)	16 (70%)	11 (63%)		
Other hospital admissions					
No (*n*, %)	11 (50%)	11 (48%)	7 (47%)	$\chi^2=0.0$[a]	0.98
Yes (*n*, %)	11 (50%)	12 (52%)	8 (53%)		

[a]Based on Pearson χ^2 test.
[b]Based on Kruskal–Wallis non-parametric test for multiple group comparison.

QoL scales (PCS and MCS) and the analyses were repeated. In multivariate regression analysis, 49.4% of variance ($R = 0.703$; $R^2 = 0.494$; R^2 adjusted $= 0.427$) of the new PCS score was predicted by the same risk factors as before: age, diabetic comorbidity, number of types of medications, INTERMED, haemodialysis as treatment, PTH and Kt/V urea. The risk factors diabetes, age, Kt/V urea and INTERMED were significant independent risk factors. With respect to MCS, 48.4% of variance was explained by the seven factors ($R = 0.695$; $R^2 = 0.484$; R^2 adjusted $= 0.415$) and age, Kt/V urea and INTERMED were significant independent predictors.

Discussion

We assessed biopsychosocial case complexity and QoL in a sample of ESRD patients under haemo- and peritoneal dialysis. We found comparable levels of QoL as have been reported elsewhere. Several baseline variables were associated with poor QoL at one year follow-up, but only three remained significant in multivariate analyses: age, diabetes as a comorbid condition and high INTERMED score. INTERMED was not independently associated with physical health and non-survival, but it was the single most important predictor of mental health, which in turn has been shown to be related to non-survival [9]. A simple risk score based on INTERMED, age ($\geq$65) and comorbid diabetes (yes/no) was associated with non-survival and with poor QoL in terms of physical and mental health among the surviving patients. In an additional analysis, in which non-survival was recoded as having a zero value in QoL, rather similar results were found: INTERMED, age and diabetes as a comorbid condition were again independent predictors of QoL. Also, Kt/V urea proved to be an independent predictor in this analysis. Our study demonstrates that detection of patients at risk of poor outcome may be relatively easy: the INTERMED score is based on a global assessment of the patient, while age and diabetes as a comorbid condition are data which are present in any patient information system.

In this study we found no relation between INTERMED and most of the variables collected at baseline, expect for the number of medications. This finding, combined with the result that INTERMED was related to QoL at follow-up, underlines the notion that QoL depends more on the patients' general vulnerability than on the severity of the illness *per se* and that some aspects of QoL may be associated with vulnerability independent of severity of illness. Remarkably, none of the clinical baseline variables were associated with poor mental health and physical health as experienced by the patient, except for having diabetes.

As a limitation of this study, the lack of a baseline QoL assessment is acknowledged. Since baseline QoL is most probably a powerful predictor of QoL after 1 year, it becomes questionable whether the INTERMED score at baseline would be related to QoL at follow-up after controlling for baseline functioning. We cannot assess this issue with the data at hand; however, the INTERMED has an important advantage over patient-rated QoL in the planning of care. Since the INTERMED is based on a review of clinically relevant data, it will be less dependent on the temporal state of mind of the patient and will provide more relevant information for the clinician. Elsewhere, we have shown that INTERMED scores are stable at 1 year follow-up ($R = 0.75$) and that INTERMED scores are associated with decisions made during interdisciplinary meetings in MS patient care.

Other limitations of the present study concern the limited number of patients, the large number of patients lost due to non-survival and the fact that we used a convenience sample rather than a strict random sample of dialysis patients. Although we have shown that attrition was not associated with any of the baseline variables, except for sex, we do feel that the study results should be seen as preliminary. The use of a convenience sample of patients may have resulted in an oversampling of complex peritoneal dialysis patients (with relatively many appointments at the ambulatory clinic). If this has influenced our findings, we do expect this effect to be small. We recommend a replication study of the utility of the INTERMED in dialysis patients in a bigger sample.

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Conflict of interest statement. None declared.

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