

Patients' representations of their end-stage renal disease: relation with mortality

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Abstract

Background. Self-regulation theory explains how patients' illness perceptions influence self-management behaviour (e.g. via adherence to treatment). Following these assumptions, we explored whether illness perceptions of ESRD-patients are related to mortality rates.

Methods. Illness perceptions of 182 patients participating in the NECOSAD-2 study in the period between December 2004 and June 2005 were assessed. Cox proportional hazard models were used to estimate whether subsequent all-cause mortality could be attributed to illness perception dimensions.

Results. One-third of the participants had died at the end of the follow-up. Mortality rates were higher among patients who believed that their treatment was less effective in controlling their disease (perceived treatment control; RR = 0.71, $P = 0.028$). This effect remained stable after adjusting for sociodemographic and clinical variables (RR = 0.65, $P = 0.015$).

Conclusions. If we consider risk factors for mortality, we tend to rely on clinical parameters rather than on patients' representations of their illness. Nevertheless, results from the current exploration may suggest that addressing patients' personal beliefs regarding the effectiveness of treatment can provide a powerful tool for predicting and perhaps even enhancing survival.

Keywords: adherence; end-stage renal disease; illness perceptions; mortality; self-regulation

Introduction

Large differences exist between patients with end-stage renal disease (ESRD) with similar clinical characteristics in how they cope and behave in response to their illness. Self-regulation theory [1] provides an explanation for this: patients construct a personal model about their illness and these personal illness representations (e.g. on curability and consequences) subsequently determine health outcomes in a variety of patient populations [2]. Among renal patients, illness perceptions are associated with quality of life [3–6], self-management behaviour [7] and treatment adherence [8]. Consequently, illness perceptions could be a risk factor for mortality, but no reports are available about whether they really are. The aim of the current study was to explore whether illness representations are related to mortality in ESRD patients, independent of sociodemographic and clinical factors.

Methods

Study outline and illness perceptions questionnaire

Data were collected within the framework of The Netherlands Cooperative Study on the Adequacy of Dialysis (NECOSAD-2) [9], a prospective observational study among incident dialysis patients without a previous history of renal replacement therapy, in which all new dialysis patients were asked for informed consent for a recurrent assessment of clinical variables and quality of life. Between December 2004 and June 2005, the Illness Perception Questionnaire-Revised (IPQ-R) [10] was administered in the mailing wave in addition to the regular measures. Hence, all patients participating in the NECOSAD assessments did receive the questionnaire. Patients' mortality was examined in September 2008 after an average of 3.5 years of follow-up.

The IPQ-R has been applied to patients with widely varying illnesses, and has satisfactory psychometric properties [10]. It was tailored to ESRD

Table 1. Dimensions of patients' illness perceptions on a five-point scale^a

IPQ-R dimensions	Mean (SD)	Description
Timeline	4.3 (0.7)	Is my ESRD permanent rather than temporary?
Cyclic timeline	3.0 (1.0)	Does my ESRD and related symptoms have a cyclical nature?
Consequences	3.5 (0.7)	Does ESRD have major consequences on my life?
Personal control	2.9 (0.7)	Can I influence ESRD by how I personally behave?
Treatment control	3.7 (0.8)	Will my treatment be effective in controlling ESRD?
Illness coherence	3.7 (0.8)	Do I have a complete understanding of my ESRD?
Emotional representation	2.6 (1.0)	Do I have lots of negative feelings about my ESRD?
Illness identity	5.2 (3.0)	Which bodily symptoms are related to my ESRD?

^aIllness identity is a sum-score of the number of symptoms that respondents attribute to their ESRD.

to assess patients' cognitive and emotional perceptions regarding their illness. Table 1 depicts each dimension of patients' illness perceptions with a short explanation. For the dimension 'treatment control', we used two items, namely 'My treatment can control my illness' and 'There is nothing which can help my condition' on a five-point scale ranging from 1 'strongly disagree' to 5 'strongly agree'.

Statistical methods

The SPSS 16.0 package was used to analyse the data. Cox proportional hazard models were used to calculate relative risks for all-cause mortality examining illness perception dimensions. The time variable referred to the moment of completing the IPQ-R questionnaire until death or censoring. Reasons for censoring included loss to follow-up (e.g. transplantation and drop-out), or end of the follow-up.

Results

Participants

Of the 246 patients, 182 completed the IPQ-R questionnaire (response rate 74.0%). Non-response was higher among younger patients ($t = 2.01$, $P = 0.045$), and non-response was somewhat higher among patients receiving peritoneal dialysis instead of haemodialysis ($\chi^2 = 3.35$, $P = 0.067$). No further differences were observed between patients who did complete the questionnaire and those who did not (i.e. regarding serum albumin, comorbidity, primary cause of renal failure, years on dialysis, education, gender, marital status). Table 2 shows sociodemographic and clinical characteristics in the period of completion of the IPQ-R. Levels of serum albumin, comorbidity (three-point Davies score) and primary kidney disease (four-category ERA-EDTA classification) were measured as indicators of illness severity. For patients with missing values at the moment of completing the IPQ-R, we used their assessments of the previous measurement (6 months earlier).

Table 2. Patient characteristics ($n = 182$)

	N (%)
Sociodemographic	
Age, mean (SD)	67.3 (11.5)
Sex, male	113 (62.1%)
Married or cohabiting	126 (69.2%)
Education, low ^a	92 (52.6%)
Medical	
Davies comorbidity score	
None	122 (67.0%)
Medium	57 (31.3%)
High	3 (1.6%)
Primary cause of renal failure	
Diabetes mellitus	21 (11.5%)
Glomerulonephritis	12 (6.6%)
Renal vascular disease	25 (13.7%)
Other cause	124 (68.1%)
Dialysis modality, haemodialysis	139 (76.4%)
Years on dialysis, mean (SD)	3.5 (2.3)
Serum albumin, mean (SD) ^a	36.1 (4.8)

^aDue to missing values some categories do not add up to 182 (missings $n < 7$).

Table 3. Relative risk of separate illness perceptions for all-cause mortality, crude and adjusted

	Unadjusted		Adjusted ^a	
	RR	95% CI	RR	95% CI
Timeline	0.95	0.66–1.38	1.07	0.71–1.63
Cyclic timeline	1.26	0.95–1.67	1.23	0.91–1.67
Consequences	1.01	0.72–1.42	0.98	0.66–1.47
Personal control	0.83	0.59–1.17	0.82	0.55–1.24
Treatment control	0.71*	0.53–0.96	0.65**	0.46–0.92
Illness coherence	0.77	0.56–1.05	0.84	0.60–1.18
Emotional representation	0.89	0.67–1.17	0.81	0.60–1.09
Illness identity	1.02	0.93–1.10	1.06	0.96–1.17

^aAdjusted for age, sex, education, marital status, Davies comorbidity, primary kidney disease, days on dialysis, dialysis modality, serum albumin. * $P < 0.05$, ** $P < 0.01$.

All-cause mortality

At September 2008, 33.5% of all patients who completed the IPQ-R had died ($n = 61$). The main cause of death was due to cardiovascular reasons (24.4%). Table 3 depicts associations between the separate illness perception dimensions and mortality. One dimension of the IPQ-R was associated with mortality: mortality rates were higher among patients who perceived their treatment as being less effective in regulating ESRD ($P = 0.028$). This effect of 'perceived treatment control' remained stable if we adjusted for clinical and sociodemographic variables (i.e. age, sex, education, primary kidney disease, comorbidity, dialysis duration, treatment modality, levels of serum albumin; $P = 0.015$).

Discussion

To our knowledge, this is the first report showing that patients' illness perceptions regarding treatment control is

related to survival. Patients who perceived their treatment to be less effective suffered from a higher level of mortality. This relation remained stable if adjusted for a range of clinical and sociodemographic variables. Different explanations may account for this. First, the patients' judgement about the treatment effectiveness may reflect subtle and important illness changes that signify a poor treatment trajectory. Self-regulation theory [1] provides another explanation: beliefs about the treatment or medication being ineffective could influence the extent to which patients feel motivated to regulate their illness and to adhere to treatment guidelines, which may seriously increase their mortality risk [11]. Further studies are needed to replicate this finding and to provide evidence for the suggested mechanism.

The current study has several limitations. First, the patient population consists of a transection of ESRD patients: some had just started dialysis treatment whereas others had survived for many years on dialysis already. Second, only primary kidney disease, comorbidity and the level of serum albumin were used as indicators of illness severity. As we did not adjust for a wider range of other clinical parameters that indicate illness severity, our results should be interpreted with some caution.

However, if illness perceptions regarding treatment control indeed pose a serious risk factor for mortality, then this provides physicians with a unique possibility to improve survival of their patients. This is because in contrast to other risk factors like age and comorbidity, illness perceptions prove to be modifiable by relatively straightforward psycho-educational interventions [12,13]. For example, they result in a better understanding of the necessity of taking phosphate binding medication in ESRD patients [13].

Conflict of interest statement. None declared.

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