Illness representations and quality of life scores in haemodialysis patients

Adrian Covic1, Anca Seica1, Paul Gusbeth-Tatomir1, Ovidiu Gavrilovici2 and David J. A. Goldsmith3

1Dialysis and Transplantation Center, ‘C. I. Parhon’ University Hospital, Iasi, Romania, 2‘Al. I. Cuza’ University, Department of Psychology, Iasi, Romania and 3Renal Unit, Guy’s Hospital, London, UK

Abstract

Background. Health-related quality of life (QoL) in haemodialysis (HD) patients is a significant predictor of mortality and hospitalization. Patients’ adaptation to a chronic disease is determined by their beliefs about illness and treatment. In this cross-sectional study we examined the impact of illness representations on QoL of HD patients and the influence of HD duration on this relationship.

Methods. Eighty-two clinically stable HD patients completed the Short Form-36 Health Survey (mean age 47.9±12.1, mean treatment duration 72±50.6, 53.6% males). Illness representations were assessed by a structured interview containing questions derived from The Revised Illness Perception Questionnaire.

Results. Our results indicate a relatively low QoL of HD patients, with an important proportion of patients scoring less than 43 for the physical component summary (65.9%) and less than 51 for the mental component summary (58.5%). HD patients consider their illness as having a chronic course, which they understand and control quite well. A higher personal control is associated with a lower emotional response and a better understanding of the disease. However, the perceived negative consequences of the disease upon patients’ personal lives are considerable, as is their emotional response. Four of the six components of illness representations were strongly related to QoL parameters. On multiple regression analysis, between 15 and 31% in the variance of the physical and mental component of QoL was explained by three dimensions of illness representations: the perceived course of the disease, personal control and emotional response. Only the emotional response dimension of the illness representations is related to treatment duration ($r = -0.48$, $P < 0.01$).

Conclusion. Our study demonstrates important relationships between illness representations and QoL in end-stage renal disease patients treated by HD. Future research will have to plan for interventions that could alter illness representations in order to confirm the real impact of illness representations upon patients’ QoL.

Keywords: end-stage renal disease; haemodialysis; illness representations; quality of life

Introduction

Recent studies show that health-related questionnaire-derived assessment of quality of life (QoL) is a strong and independent predictor of mortality and hospitalization in dialysis patients [1,2]. The Medical Outcomes Study Short Form-36 (MOS SF-36) measures QoL by investigating eight dimensions, which contribute to the evaluation of two major aspects of patients’ functioning [3]: physical (physical component summary, PCS) and mental (mental component summary, MCS). A 1-point increase in PCS is associated with a 2% reduction of the mortality rate and odds of hospitalization, even after controlling for demographic variables and co-morbidities, the same is true for MCS as a mortality predictor [2]. Most important, the information provided by this self-assessment report may not be available through any other single instrument/method [2]. Consequently, detailed assessment of the variables, which influence the QoL of haemodialysis (HD) patients is an important objective.

Recent studies in chronic diseases suggest that QoL may be related to patient cognitive representations of illness and treatment, according to a theoretical self-regulation model of illness appraisal and behaviour [4]. This self-regulation model involves a central stage of cognitive representation of the health threat. The illness representation derives from prior experiences in the medical domain and guides the processing of
information in a fashion consistent with prior knowledge [5,6]. The second stage is coping, which involves the selection and performance of a plan to deal with various/changing disease threats. Illness representations are multi-dimensional: disease identity (labeling the disease and understanding the disease symptoms), cause, consequences (perceived physical, psychological, social and economic impact of the disease), time-line (perceived course of the disease) and controllability (perceived management of the disease).

A direct influence of illness representations on QoL has been demonstrated in various chronic conditions: diabetes [7], chronic fatigue syndrome [8,9], Addison disease [10] and multiple sclerosis [11]. Unfortunately, since illness representations may vary widely across different chronic diseases and even among patients who suffer from the same medical condition [12], their relationship with QoL cannot be extrapolated to end-stage renal disease (ESRD). There are no previous published data concerning illness representations assessment in ESRD patients.

Given the importance of health-related QoL measures in predicting patients’ outcome and the modifiable nature of illness representations held by patients we aimed to determine the relationship between HD patients’ beliefs about disease and treatment and their QoL. Do illness representations predict QoL of HD patients? And if so, does treatment duration play a role in this association?

Subjects and methods

Study population

All clinically stable HD patients without significant comorbidities (n = 90) from the Dialysis and Renal Transplantation Center, University Hospital ‘Dr. C. I. Parhon’ Iasi, Romania were invited to participate. Exclusion criteria: congestive heart failure, ischaemic heart disease, chronic lung disease, severe chronic liver disease, neoplasia. A total of 82 patients (mean age 47.9 ± 12.1, mean treatment duration 72 ± 50.6, 53.6% males) agreed to participate and completed the assessment questionnaires for health-related QoL and illness representations.

Instruments

The Short Form Health Survey Questionnaire (SF-36) adapted for Romanian population [13] was used to assess eight dimensions of the 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 physical functioning, role-functioning physical, vitality, bodily pain and general health perceptions) and one for the mental component (assessing social functioning, role-functioning emotional, mental health, vitality and general health perceptions). Scores range from 0 to 100, a higher score indicating a better QoL.

Illness representations were assessed with the well-validated Revised Illness Perception Questionnaire, a recently developed and widely used quantitative measure of the five components of illness representations in Leventhal’s self-regulatory model [4]. Furthermore this instrument had been successful in predicting different aspects of adaptation and recovery in chronic illness [14]. Through a number of structured questions the following six components of illness representations were evaluated: time-line, consequences, personal control, treatment control, coherence and emotional (see below for details). The patients rated the items on a four-point scale, ranging from ‘strongly disagree’ to ‘strongly agree’. The reliability scores (Chronbach’s alpha) for the six components of illness representation were comparable with those found in other studies assessing dimensions of illness representations [8,10].

The time-line dimension was assessed by six items (α = 0.62); 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 six items (α = 0.64), a higher score indicating that the patient considered their disease as having serious consequences upon their life (e.g. ‘My illness strongly affects the way others see me’).

Personal control dimension comprised five items (α = 0.70); 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 of the disease.

Treatment control was assessed by five items (α = 0.68), a higher score indicating that the patient considers HD efficient in controlling ESRD (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 five items (α = 0.63); a higher score on this dimension indicating that patient considers to understand ESRD (e.g. ‘My illness doesn’t make any sense to me’).

The last dimension assessed—emotional response—had six items (α = 0.74); 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’.

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

Statistical analysis was performed using SPSS 7.5 for Windows. Correlation analysis was performed using Spearman’s rho. Comparisons were made using the χ² test. Multiple stepwise regression analysis was used to predict independent variables affecting QoL. Initially simple correlations were examined between age, gender, treatment duration and PCS and MCS as dependent variables. As none of these independent variables were significantly related to QoL scores they were excluded as predictors from the final regression analysis. A model was constructed using PCS and MCS as dependent variables and the dimensions of illness representations as independent variables. A P value of 0.05 or less was considered to indicate statistical significance.

Results

Demographics and clinical data are shown in Table 1. The study population MOS SF-36 summary scores compared with the reference Romanian general
population [15] and a similar Romanian HD population [13] are presented in Table 2. For comparison, also shown in Table 2 are results from a large US dialysis population, where the relationship between QoL measures and outcomes was prospectively assessed [2]. Lowrie et al. [2] calculated that PCS scores lower than 43 and MCS scores less than 51 are associated with an increasing risk of death. An important proportion of our patients had low QoL scores: 65.9% less than 43 and 58.5% less than 51 for PCS and MCS, respectively. There was no significant difference in the prevalence of patients who obtained low PCS and MCS scores when subjects with a short treatment duration (<1 year, group A, n = 36, mean HD duration of 5.7 months), where compared with those with a longer treatment history (>6 years, group B, n = 46, mean HD duration of 103.4 months)—see also Table 1 for demographic characteristics in the two subgroups.

Illness representation scores for the six dimensions assessed are presented in Table 3. Our patients view their illness as having a chronic course; they understand it quite well and consider that it can be influenced by their own actions. However, at the same time, the perceived negative consequences of the disease upon their lives are considerable, as is their emotional response. Similarly to the QoL analysis (see above) we found that there was no significant difference between the illness representations held by ‘new’ HD patients (group A) vs patients with a longer treatment history (group B, Table 3).

Important information regarding illness representations may be derived by analysis of the relationship between individual components in the studied population. Correlations between the dimensions of illness representations for the two groups of patients are presented in Table 4. A better understanding of illness...
Illness representations in HD

Table 4. Correlations between illness representations dimensions

<table>
<thead>
<tr>
<th></th>
<th>Emotional response</th>
<th>Personal control</th>
<th>Time-line</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coherence</td>
<td>−0.42&lt;sup&gt;a&lt;/sup&gt;</td>
<td>0.56&lt;sup&gt;b&lt;/sup&gt;</td>
<td>ns</td>
</tr>
<tr>
<td>Consequences</td>
<td>0.52&lt;sup&gt;b&lt;/sup&gt;</td>
<td>ns</td>
<td>ns</td>
</tr>
<tr>
<td>Personal control</td>
<td>ns</td>
<td>1.00</td>
<td>0.47&lt;sup&gt;a&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

<sup>a</sup>P < 0.05.
<sup>b</sup>P < 0.01.

Consequences = perceived physical, psychological, social and economical impact of the disease; coherence = perceived understanding of the disease; emotional response = emotional reaction to the disease; personal control = perceived personal management of the disease; time-line = perceived course of the disease.

Table 5. Correlations between illness representations, QoL and treatment duration

<table>
<thead>
<tr>
<th></th>
<th>Coherence of QoL</th>
<th>Emotional response</th>
<th>Personal control</th>
<th>Time-line</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical component</td>
<td>ns</td>
<td>−0.43&lt;sup&gt;a&lt;/sup&gt;</td>
<td>ns</td>
<td>0.40&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>Mental component of QoL</td>
<td>0.42&lt;sup&gt;a&lt;/sup&gt;</td>
<td>−0.41&lt;sup&gt;b&lt;/sup&gt;</td>
<td>0.37&lt;sup&gt;a&lt;/sup&gt;</td>
<td>ns</td>
</tr>
<tr>
<td>Treatment duration</td>
<td>ns</td>
<td>−0.48&lt;sup&gt;b&lt;/sup&gt;</td>
<td>ns</td>
<td>ns</td>
</tr>
</tbody>
</table>

<sup>a</sup>P < 0.05.
<sup>b</sup>P < 0.01.

was associated with a lower emotional response to the disease but of the higher personal control upon disease. Patients who had a lower emotional reaction to the disease also considered that ESRD does not significantly impact their lives. At the same time, the perception of a chronic course of the disease was associated with a better personal control. Only the treatment control dimension was not related to any of the other five dimensions of illness representations evaluated.

The relationships between illness representations, QoL and treatment duration were also analysed (Table 5). Only the emotional response dimension of the illness representations is related to the treatment duration (−0.48, P < 0.01), suggesting that for patients with longer treatment history, ESRD has a lower emotional impact. At the same time, patients with a lower emotional response to the disease obtained better PCS and MCS scores. Additionally, patients who tried to understand and to control their illness obtained better scores in the mental component of QoL. Finally, patients who considered their illness as having a chronic course obtained better PCS scores. No association was found between treatment duration and QoL of our patients.

A multiple regression analysis was also performed (see Tables 6 and 7). Only three dimensions of illness representations proved to be significantly associated with the QoL of our patients: time-line for the physical component, personal control for the mental component and emotional response for both components.

Table 6. Multiple regression analysis for the physical component of QoL

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>Adjusted R²</th>
<th>P</th>
<th>95% confidence intervals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time-line</td>
<td>0.42</td>
<td>0.30</td>
<td>0.02</td>
<td>[1.93, 22.01]</td>
</tr>
<tr>
<td>Emotional response</td>
<td>−0.57</td>
<td>0.15</td>
<td>0.003</td>
<td>[−24.6, −1.92]</td>
</tr>
</tbody>
</table>

Table 7. Multiple regression analysis for mental component of QoL

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>Adjusted R²</th>
<th>P</th>
<th>95% confidence intervals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional response</td>
<td>−0.41</td>
<td>0.31</td>
<td>0.01</td>
<td>[−25.1, −2.6]</td>
</tr>
<tr>
<td>Personal control</td>
<td>0.48</td>
<td>0.17</td>
<td>0.006</td>
<td>[3.5, 33.9]</td>
</tr>
</tbody>
</table>

Discussion

The aim of the present study was to describe, for the first time, in a well haemodialysed population without significant confounding co-morbidities, cognitive representations held by ESRD patients, and to examine the impact of these representations on QoL. Our results indicate a relatively low QoL—similar to other national and a large US dialysis data. As expected, QoL of HD patients from our study was lower than that of the healthy population in Romania. Mihaila and colleagues [15] reported in the general population a mean of 64.4 for PCS and of 63.8 for MCS (60.8 and 60.0, respectively, for the age group 45–54 years—similar to our patients) when validating the Romanian version of the MOS SF-36. The magnitude of the difference between renal patients on dialysis and healthy subjects is consistent with results from other comparable national studies in ESRD populations [13], but greater than that reported by Lowrie in a large US dialysis population [2]. This is mostly due to the differences in MCS and PCS scores for the healthy/normal subjects between countries.

HD patients consider their illness as having a chronic course, which they understand quite well and are able to control. A better understanding of the illness is associated with a lower emotional response and higher personal control of the disease. At the same time, the perception of a chronic course of the disease is associated with better personal control. However, the perceived negative consequences of the disease upon patients’ personal lives are considerable, as is their emotional response.

According to Leventhal and colleagues [16] the illness representation dimensions are interrelated. They function as groups of beliefs instead of single cognitions. Our results confirm this statement for ESRD patients on HD, demonstrating significant correlations between five of the six components of illness representations assessed. The fact that the treatment control dimension was not associated with
any other dimension may be due to the cross-sectional design of our study.

It is important to discuss here the implications of a chronic illness schema held by dialysis patients. Previous research in non-renal populations indicates that patients who consider their illness as having a chronic course are more disabled in daily functioning [17] and show little inclination to engage in activities designed to control their illness [18]. This, however, is not true in HD patients. In fact, our study suggests that an increased perception of the disease chronicity is positively and significantly associated with better personal control and physical functioning. This contradiction may lie in the conceptualization of chronicity as a function of how much the disease interferes with daily life [17]. In well-dialysed patients without important co-morbidities the only interference of the disease with their lives is the fact that they have to come to treatment, in some cases for a long time. On the other hand a non-negligeable proportion of patients fail to comply with the prescribed medical regimens just because they think and hope that: ‘my kidneys will regain functions one day’. A patient admitted that he held this wrong belief for no < 9 years. This is why we consider that holding a chronic illness schema is essential for the adaptation of our patients. This assumption was confirmed by multiple regression analysis.

Consistent with the self-regulation model [4] the adaptive outcome depends on coping, which in turn depends on illness representations. Our study demonstrates that three illness representation dimensions—the chronicity perception (see above), personal control and the emotional response—have the potential to be powerful predictors of QoL in ESRD patients. Future prospective analysis will have to reinforce this important finding. The role of coping—a much weaker predictor of QoL in non-renal populations [9,10]—remains also to be ascertained in a prospective design. Finally, future research will have to plan for interventions that could alter illness representations—for example fostering patients’ understanding of ESRD and reducing the emotional response to their illness and treatment modality—in order to confirm the real impact of illness representations upon patients’ QoL.

Our findings are consistent with those obtained in other chronic but non-renal diseases. Particularly, emotional response and personal control also predicted the QoL of patients with chronic fatigue syndrome, Addison disease and multiple sclerosis [8,9,11]. Moreover, a study in type 1 and type 2 diabetes patients showed that understanding the nature of the diabetic disease and a superior perceived control of diabetes were significant predictors of engagement in diabetes-specific health behaviours and positive perceptions of QoL [7]. All these findings suggest a common mechanism of adaptation to chronic illnesses [9].

Our data suggest that time on HD has a minor influence on illness representations and QoL of our patients. There was no significant difference between illness representations held by new HD patients vs patients with a longer treatment history. Treatment duration seems to be associated only with a lower emotional response to disease. Although these findings are consistent with some recent studies including a small number of patients [19], we acknowledge the inherent limitations of a cross-sectional analysis and the requirement of a longitudinal testing of this important point.

Our findings confirm in ESRD the central assumption of the self-regulation theory [4], which states that in order to adapt to an illness, a patient behaves rationally, according to his personal model of disease and treatment. Illness representations held by HD patients are particular and therefore important to be recognized and assessed for optimal patient care. This is further supported by the described link between cognitive representations and QoL. Given the potential critical role of illness representations and the fact that adaptation to a chronic illness is a continuous process we advocate the initiation of a prospective trial assessing the QoL and the patients’ personal models of illness and treatment.

Conflict of interest statement. None declared.

References


Received for publication: 25.11.03
Accepted in revised form: 10.03.04