

# Impact of measurement timing and intradialytic symptoms on patient-perceived quality of life

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## ABSTRACT

**Objective:** To determine the relationship between patients' perceived quality of life on hemodialysis, the timing of its measurement, and the number of symptoms/complications occurring during the session.

**Material and Method:** Longitudinal observational study in hemodialysis patients with preserved cognitive capacity. Sociodemographic and clinical variables and quality of life were collected using the Coop-Wonka instrument. The study was conducted in 2 phases:

**First phase:** pre-HD quality of life evaluation, self-administered questionnaire (12 hours before the 1st weekly session).

**Second phase:** 4 weeks later, completion of the same quality of life questionnaire, administered by nursing staff at the end of the 1st weekly session.

All symptoms, mechanical complications, and stress situations experienced by the patient during the sessions were recorded for four weeks.

**Results:** Sixty-one patients were studied, 39 men (64%). The mean age was  $67.7 \pm 13$  years. Time on hemodialysis was  $68.7 \pm 79$  months. Overall scores for health-related quality of life were  $25.6 \pm 6.9$  points (1st phase) and  $24.2 \pm 7$  points (2nd phase), with significant differences between both periods. 328 symptoms were recorded ( $0.44 \pm 0.54$ /patient and session). Time on hemodialysis was related to symptomatology and quality of life, pre-session and post-session. Symptomatology was related to health-related quality of life pre and post-session.

**Conclusions:** Patients who have been on hemodialysis for more extended periods have worse quality of life and more symptoms during the sessions. Their perception of their health status is better post-session compared to pre-dialysis sessions.

**Keywords:** hemodialysis session; health-related quality of life; symptomatology.

## RESUMEN

**Impacto del momento de medición y de la sintomatología acontecida durante la hemodiálisis en la calidad de vida percibida por el paciente**

**Objetivo:** Determinar la relación entre calidad de vida percibida por el paciente en hemodiálisis, el momento de medición de esta y el número de síntomas/complicaciones acontecidos durante la sesión.

**Material y Método:** Estudio observacional longitudinal en pacientes en hemodiálisis con capacidad cognitiva conservada. Se recogieron variables sociodemográficas y clínicas, así como calidad de vida mediante instrumento Coop-Wonka. El estudio se desarrolló en 2 fases:

**Primera fase:** evaluación calidad de vida preHD, cuestionario autoadministrado (en las 12 h previas a 1ª sesión semanal).

**Segunda fase:** 4 semanas más tarde, cumplimentación del mismo cuestionario de calidad de vida, administrado por enfermería (al finalizar 1ª sesión semanal).

Durante cuatro semanas se recogieron todos los síntomas, complicaciones mecánicas y situaciones de estrés experimentadas por el paciente durante las sesiones.

**Resultados:** Se estudiaron 61 pacientes, 39 hombres (64%). Edad  $67,7 \pm 13$  años. Tiempo en hemodiálisis  $68,7 \pm 79$  meses. Las puntuaciones globales de calidad de vida relacionada con la salud fueron  $25,6 \pm 6,9$  puntos (1ª fase) y  $24,2 \pm 7$  puntos (2ª fase), con diferencias significativas entre ambos periodos. Se registraron 328 síntomas ( $0,44 \pm 0,54$ /paciente y sesión). El tiempo en hemodiálisis se relacionó con sintomatología y calidad de vida, pre-sesión y post-sesión. Y la sintomatología se relacionó con calidad de vida relacionada con la salud pre y post-sesión.

**Conclusiones:** A mayor tiempo en hemodiálisis los pacientes presentan peor calidad de vida y más sintomatología durante las sesiones. La percepción sobre su estado de salud, es mejor post-sesión en comparación con la percibida antes de la sesión de diálisis.

**Palabras Clave:** sesión de hemodiálisis; calidad de vida relacionada con la salud; sintomatología.

## INTRODUCTION

Health-related quality of life (HRQoL) is a concept that evaluates an individual's health status based on their own perception of the effects of a disease or of a given treatment, across different aspects of life such as physical, emotional, and social well-being<sup>1</sup>.

Over recent decades, HRQoL has become an essential measure of the impact of health care on patients, as it is now widely recognised that traditional clinical outcome measures are insufficient to fully assess the effects of an intervention. HRQoL provides a more comprehensive evaluation<sup>2</sup>.

Thus, the focus has shifted from relying exclusively on physicians' judgments of patients' health based on objective clinical markers to valuing patients' own perceptions of their health status<sup>3</sup>.

Patients on haemodialysis (HD) receive renal replacement therapy frequently (on average, 3 sessions per week) and are subjected to multiple medical interventions, which in routine clinical practice are assessed almost exclusively using objective data. At present, patients on HD in our setting generally achieve clinical results that exceed expectations. However, parameters that define "adequate dialysis" and demonstrate technical efficiency provide little insight into how patients perceive their own health. For this reason, assessing HRQoL is necessary to gain a more complete understanding of the outcomes of our interventions<sup>4-6</sup>.

At present, numerous validated instruments are available to measure HRQoL. Some of these are generic, while others are more specific and designed for patients with particular conditions. All of them are considered feasible tools because of their ease of application; they are reliable, valid for measuring what they intend to measure, and sensitive to change, as they can detect improvement or deterioration in the patient's health status after a health intervention. They also have clinical significance because they allow assessment of the magnitude of a treatment's effect by asking patients directly about the changes they perceive in their HRQoL<sup>7</sup>.

HD sessions are health interventions during which clinical complications can occur, affecting patient well-being<sup>8</sup>. Even when uneventful, sessions are burdensome for most patients, limiting work and leisure activities, and potentially affecting emotional health (anxiety and depression) and social relationships<sup>9</sup>.

Indeed, numerous studies have shown that HRQoL is significantly impaired in dialysis patients compared with the general population<sup>10</sup>. However, to our knowledge, no studies have specifically evaluated the impact of HD sessions themselves on patients' health perceptions.

Given that HD sessions are often uncomfortable and negatively affect patients' health perceptions, our objective was to determine whether HD sessions and their degree of comfort influence patients' perceived HRQoL.

## MATERIAL AND METHOD

### Study setting

The study was conducted in the Nephrology Department of *Hospital Universitario Reina Sofía* (Córdoba, Spain), including the hospital-based dialysis unit, a peripheral dialysis centre, and a contracted Fresenius Medical Care centre, between March and April 2023.

### Design

We conducted a longitudinal observational study.

### Population and sample

The study population comprised patients with advanced chronic kidney disease enrolled in chronic HD programmes at these three dialysis units, with all patients eligible for inclusion. Inclusion criteria were age >18 years; preserved cognitive abilities sufficient to complete the HRQoL questionnaire; and acceptance to participate in the study through signed informed consent.

Exclusion criteria were worsening of any chronic condition, onset of any acute condition, or hospital admission during the study period.

A total of 61 patients were finally included: 39 men (64%) and 22 women (36%), mean age  $67.7 \pm 13$  years, and mean time on HD  $68.7 \pm 79$  months.

### Study variables

The outcome variable was HRQoL.

All symptoms or events occurring during the study sessions were recorded. In addition, demographic variables (age and sex), clinical variables (type of vascular access, dialysis adequacy index [Kt/V]), Charlson comorbidity index (CCI), and biochemical parameters (haemoglobin [Hb] and albumin) were collected.

### Instruments and data collection

HRQoL was assessed using the Coop/Wonca questionnaire, Spanish adapted version, a validated generic instrument already used in other patient groups, demonstrating adequate psychometric quality<sup>10-11</sup>.

This questionnaire assesses physical activity, emotional state, activities of daily living, social activities, perceived health status and quality of life, pain, and social support. It has proven to be reliable and sensitive to changes over time (test-retest reliability)<sup>10</sup>. It was selected for this study mainly for its feasibility, since it imposes minimal burden on both patients and professionals. It is simple, engaging, clear in question formulation, and brief. The questionnaire consists of 9 items referring to the patient's status over the past month, with five possible answers illustrated by representative drawings, on a five-point Likert-type ordinal scale, where lower scores indicate better health status. These features allow short completion time and rapid scoring and interpretation.

The study was conducted in two phases. In the first phase, HRQoL questionnaires were distributed to patients in sealed envelopes, with instructions to complete them at home in self-administered form, during the long weekend break, in the 12 hours prior to the first haemodialysis session of the week.

During the following four weeks (12 sessions), all symptoms, clinical or mechanical complications, or stressful situations experienced by the patient were recorded using a custom-designed log, based on observation or verification by the responsible nurse. These were considered as events potentially affecting patient comfort during the sessions, with the statistical treatment based on the number of symptoms or events per session.

After these four weeks, in the second phase, the same HRQoL questionnaire was administered again, this time by nursing staff at the bedside, at the end of the first weekly haemodialysis session, through a patient interview.

### Statistical analysis

For quantitative variables, the mean  $\pm$  standard deviation and the median with interquartile range were calculated, depending on whether or not they followed a normal distribution. Student's *t* test was used for comparison of means in normally distributed variables, and the Mann-Whitney *U* test for those not normally distributed. Qualitative variables were expressed as frequency distributions. Possible associations were analysed using Pearson's test for normally

distributed variables and Spearman's correlation test for non-normally distributed variables.

Data analysis was performed using SPSS version 25. Statistical significance was set at  $p < 0.05$ .

### Ethical considerations

This study was conducted in full compliance with the ethical principles set out in the Declaration of Helsinki. All participating patients provided informed consent, with assurance that all records generated would be safeguarded by the principal investigator and identified solely by the assigned case number. Data confidentiality was strictly maintained in accordance with the updated Spanish Organic Law 3/2018 of 5 December on the Protection of Personal Data and Guarantee of Digital Rights. Participants were informed that they could voluntarily withdraw from the study at any time.

## RESULTS

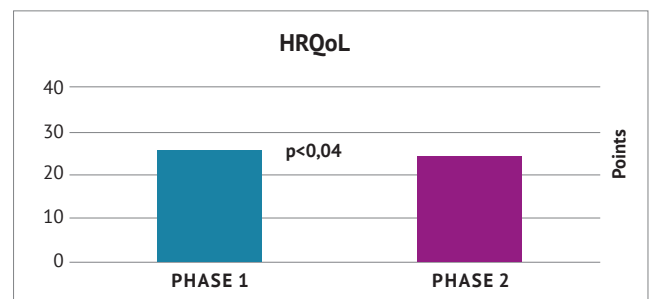
Of the 61 patients studied, 43% had diabetes, and 66% had an arteriovenous fistula (AVF) as vascular access, whereas 34% carried a central venous catheter (CVC).

The study sample had a mean CCI of  $6.5 \pm 2$  points. Mean biochemical parameters were haemoglobin (Hb)  $11.2 \pm 1.5$  g/dL and albumin  $3.8 \pm 0.3$  g/dL, with a mean dialysis adequacy index (Kt/V) of  $1.66 \pm 0.32$ .

Analysis of relationships between variables showed that age was significantly correlated with comorbidity ( $r = 0.61$ ,  $p < 0.01$ ), with older patients presenting higher CCI values.

Regarding HRQoL, overall scores are shown in **figure 1**, with significant differences between the two measurements ( $p < 0.04$ , Wilcoxon test) and good correlation between them ( $r = 0.61$ ,  $p < 0.01$ ).

During the 4-week period between the two study phases, a total of 328 symptoms were recorded ( $0.44 \pm 0.54$  per patient per session).



**Figure 1.** Mean scores of Health-Related Quality of Life between the two phases of the study.

HRQoL: Health-Related Quality of Life.

This symptomatology was correlated with time on HD ( $r=0.49, p<0.01$ ), with patients on longer-term HD presenting a greater number of symptoms during sessions. In addition, a relationship was found between overall HRQoL scores in both phases and the presence of symptoms ( $r=0.30, p<0.05$  and  $r=-0.37, p<0.01$ , respectively), indicating that patients with poorer HRQoL reported more symptoms.

No other significant relationships were identified.

## DISCUSSION

This study was designed on the theoretical hypothesis that the HD session per se is distressing for the patient and negatively affects their perception of health status.

Although the study sample is too small to allow extrapolation of our conclusions to larger populations, its demographic characteristics in terms of age and sex distribution are consistent with those reported in previous studies conducted in our setting, notably the high mean age and the predominance of men over women. In this sense, the sample may be considered representative of the haemodialysis (HD) population<sup>13-16</sup>.

In addition, as in numerous studies on patients undergoing HD, we found a significant relationship between age and the high CCI observed in our cohort<sup>10,13,17</sup>.

Regarding the biochemical parameters assessed (Hb, albumin, and Kt/V), although these do not provide an exhaustive evaluation, they suggest that this group of patients had an acceptable nutritional status and anaemia profile and received a dialysis dose slightly above that recommended in clinical practice guidelines<sup>18</sup>.

As for the overall HRQoL scores recorded in the questionnaires—showing a moderate impairment with mean scores of 25 and 24 out of 45—our sample is also in line with previously published studies that have described lower HRQoL levels in HD patients compared with the general population<sup>8,10,19,20</sup>.

These considerations suggest that our cohort represents a group of stable HD patients who are receiving effective and adequate treatment, with an acceptable self-perceived health status adjusted to what is expected in our environment.

Nevertheless, we were struck by what we consider to be a high incidence of distressing symptoms reported by patients during HD sessions, and by their association with perceived HRQoL. Patients reporting poorer HRQoL were also those with the greatest symptom burden, which runs counter to our initial hypothesis that patients would report improved perceived health status after HD sessions despite experiencing symptoms during them.

This finding, which cannot be fully explained within the scope of this study, may be largely attributable to impairment in the physical dimension of HRQoL assessed by the questionnaire. It is evident that before and after an HD session, patients experience relief from uraemic toxins and volume overload, leading to improved physical well-being. However, other HRQoL dimensions assessed by the questionnaire—such as emotional status, daily activities, social activities and support, pain, and overall health perception—are dimensions that change over time as a result of the patient's adaptive process to their health condition.<sup>21</sup> These are less likely to be modified by a single HD session or by any specific health care intervention. This could explain why patients with longer time on HD programmes reported poorer HRQoL, as their extended adaptation process may have negatively affected these dimensions.

The main limitation of this study is the small sample size for this type of research. Additionally, the different methods used to administer the quality-of-life questionnaire may have introduced uncontrolled bias.

More rigorous studies with broader samples and more outcome variables controlled for would be necessary to confirm these observations.

In summary, and in light of our findings, we conclude that in our setting, patients with longer duration on HD programmes report poorer HRQoL and greater intradialytic symptom burden. However, this does not preclude them from experiencing some improvement in their perception of health status after HD sessions compared with before.

## Conflicts of interest

None declared.

## Funding

None declared.

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