



PRO: Patient-Reported Outcome Scale for Chronic Kidney Disease

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ABSTRACT

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Background: Patients with end-stage renal disease (ESRD) suffer from a wide range of burdensome symptoms that persist despite adequate dialysis as measured by standard solute clearance parameters. Patient-reported outcome measures (PROMs) offer a structured approach to systematically identify and address this symptom burden.

Methods: A cross-sectional descriptive study was conducted in the nephrology department of CHU Ibn Rochd, Casablanca. Thirty-three patients on regular hemodialysis for at least one year were included. Demographic, clinical, and biochemical data were collected, and comorbidity burden was assessed using the Charlson Comorbidity Index. Symptom burden was evaluated using the IPOS-Renal questionnaire, which covers 15 physical symptoms and emotional items scored on a 5-point scale (0–4) over the preceding 7 days. Statistical analyses were performed using SPSS, with significance set at $p < 0.05$.

Results: The mean age was 55.4 ± 11.5 years; 40% were female. The most prevalent moderate-to-severe symptoms (≥ 2) were fatigue/lack of energy (~70%), sleep disturbances (~64%), pruritus (~61%), somnolence (~52%), restless legs (~49%), decreased appetite (~45%), and pain (~39%). Anxiety/worry was reported at a moderate-to-severe level in ~55% of patients. Total IPOS score correlated positively with the Charlson Comorbidity Index ($\rho \approx +0.42$, $p \approx 0.015$) and negatively with serum albumin ($\rho \approx -0.36$, $p \approx 0.041$).

Conclusion: The symptom burden in hemodialysis patients remains high despite dialysis adequacy. Fatigue, sleep disorders, and pruritus are the most frequent and distressing complaints. Symptom load is associated with comorbidity and nutritional status, highlighting the need for an integrated management approach combining symptom control, nutritional support, and comorbidity management.

KEYWORDS:

patient-reported outcomes; chronic kidney disease; hemodialysis; IPOS-Renal; symptom burden; quality of life; pruritus; fatigue; Charlson Comorbidity Index

1. INTRODUCTION

Patients with end-stage renal disease (ESRD) suffer from a multitude of distressing symptoms. Optimal identification and appropriate management of symptoms associated with renal failure have the potential not only to facilitate symptom relief, but also to improve overall quality of life. This heavy burden of physical and emotional symptoms is observed despite the provision of "adequate dialysis" as assessed by solute clearance measures, and despite standard nephrological care.

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The objective of our study is to present a scientific and efficient approach for the evaluation of clinical symptoms in chronic kidney disease (CKD) through patient-reported outcome measures (PROs).

2. MATERIALS AND METHODS

2.1. Demographic and Clinical Data Collection

This is a cross-sectional descriptive study conducted in the nephrology department of CHU Ibn Rochd, Casablanca. We included patients on regular hemodialysis for at least one year. Baseline characteristics were obtained from patient histories, medical records, and nephrologist diagnoses, including age, sex, body mass index (BMI), and comorbidities. The Charlson Comorbidity Index (CCI) was used to measure comorbidity burden.

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2.2. Biochemical and Dialysis Parameters

Baseline biochemical and hematological parameters were obtained from medical records, including serum creatinine, urea, hemoglobin, and serum albumin. Blood samples were collected at the start of dialysis sessions. Baseline dialysis parameters were obtained from dialysis records, including years on dialysis, dialysis prescription, and dialysis adequacy.

2.3. Symptom Data Collection

The Integrated Palliative Care Outcome Scale (IPOS) questionnaires are a series of patient-reported outcome measures (PROMs) used in various chronic disease populations. The IPOS-Renal inventory was modified for CKD and dialysis populations. It includes 15 physical symptoms related to chronic kidney disease:

- Pain
- Breathlessness
- Weakness/lack of energy
- Nausea
- Vomiting
- Loss of appetite
- Constipation
- Mouth pain or dryness
- Drowsiness
- Reduced mobility
- Itching
- Difficulty sleeping
- Restless legs
- Skin changes
- Diarrhea

Patients are asked to indicate to what extent each symptom has affected them over the preceding 7 days on a 5-point scale: 0 = not at all, 1 = slightly, 2 = moderately, 3 = severely, 4 = overwhelmingly. Emotional symptoms, including "feeling anxious or worried" and "caregiver anxiety", as well as adequate communication and other practical concerns, are assessed using the same scale.

The symptom management approach is systematic, involving prioritization of the most distressing physical and emotional symptoms, implementation of evidence-based interventions, nutritional support, psychosocial counseling, and family support. Statistical significance was set at $p < 0.05$. Analyses were performed using SPSS software.

3. RESULTS

Thirty-three hemodialysis patients were included. Mean age was 55.4 ± 11.5 years; 40% were female. Mean BMI was 24.6 ± 3.7 kg/m². Median Charlson Comorbidity Index score was 4 [3–5]. Median dialysis vintage was 3.0 [1.6–4.5] years. The majority were dialyzed three sessions per week (92%), with a 4-hour session duration in 61% of patients.

Pre-dialysis laboratory parameters showed a mean hemoglobin of 10.8 ± 1.1 g/dL and a mean serum albumin of 3.80 ± 0.35 g/dL.

IPOS-Renal symptom prevalence (\geq moderate, score ≥ 2):

1. Fatigue/lack of energy: ~70%
2. Sleep difficulties: ~64%
3. Pruritus: ~61%
4. Somnolence: ~52%
5. Restless legs: ~49%
6. Loss of appetite: ~45%
7. Pain: ~39%

The lowest-prevalence symptoms (≥ 2) were diarrhea (~12%) and vomiting (~15%). Emotional symptoms showed anxiety/worry ≥ 2 in ~55% of patients and caregiver concern ≥ 2 in ~30%.

The total IPOS score was high and highly variable between patients. Non-parametric (Spearman) correlation analyses showed that total symptom burden correlated positively with the Charlson Comorbidity Index ($\rho \approx +0.42$, $p \approx 0.015$), negatively with serum albumin ($\rho \approx -0.36$, $p \approx 0.041$), with a negative trend for hemoglobin ($\rho \approx -0.29$, $p \approx 0.105$), and no clear association with age.

In this cohort, fatigue, sleep disturbances, and pruritus were the most frequent and distressing complaints. Symptom burden increased with comorbidity and was associated with nutritional status markers (albumin), suggesting the value of a combined approach addressing symptoms, comorbidities, and nutrition—regardless of dialysis adequacy.

Figure 1 : Prevalence des symptômes IPOS-Renal (score ≥ 2) chez 33 patients hemodialyses

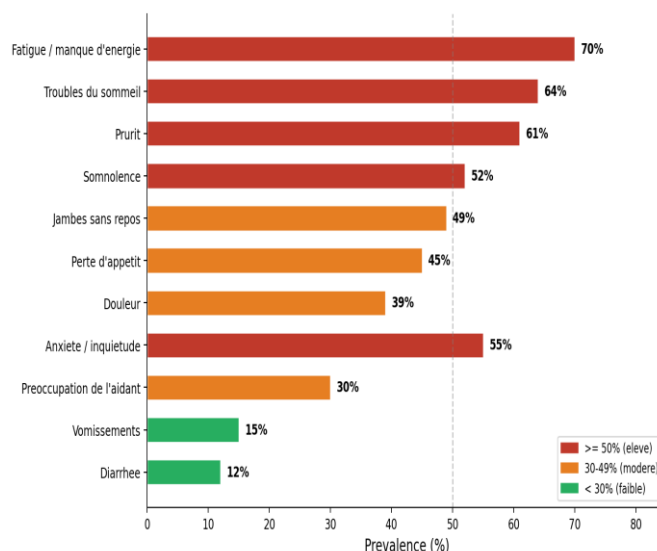


Figure 1: Prevalence of IPOS-Renal symptoms (score ≥ 2) in 33 hemodialysis patients. Red bars indicate symptoms affecting $\geq 50\%$ of patients; orange 30–49%; green $< 30\%$.

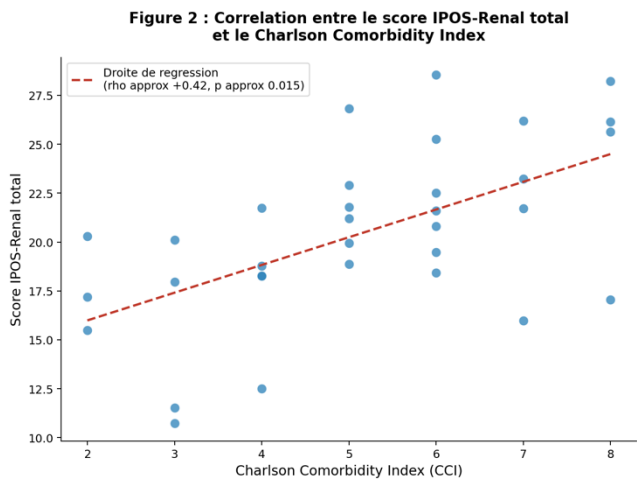


Figure 2: Relationship between symptom burden and Charlson Comorbidity Index.

4. CONCLUSION

Survival and quality of life in hemodialysis patients remain poor despite considerable research efforts. Existing trials often report surrogate outcomes that may not be relevant to patients and clinicians. The systematic use of patient-reported outcome measures such as IPOS-Renal enables a more patient-centered assessment of symptom burden and represents a valuable complementary tool in the routine clinical management of CKD patients on hemodialysis.

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