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# Living with chronic kidney disease – Perceptions of illness and health-related quality of life

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# ABSTRACT

## Living with chronic kidney disease – Perceptions of illness and health-related quality of life

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This thesis comprises two studies concerning illness perceptions and perceived health-related quality of life (HRQoL) in patients with chronic kidney disease (CKD). The overall aim was to evaluate psychometric properties of a Swedish translation of the Revised Illness Perception Questionnaire (IPQ-R) (study I), and furthermore to explore illness perceptions (study I) and HRQoL (study II) in adult patients in different stages of renal insufficiency (CKD stages 2-5). In **study I**, evidence for construct validity was gathered through cognitive interviews (N=7) and other psychometric assessments (n=54). The results supported construct validity of the IPQ-R in a CKD context. The most supported IPQ-R dimensions were identity, timeline cyclical, consequences and emotional representations. The illness coherence, timeline and controllability dimensions need to be further explored in this patient group. Most IPQ-R dimensions distinguished illness perceptions between groups of different CKD stages and symptom burden. The patients in earlier CKD stages (CKD stages 2-3) or with <8 symptoms did not hold as strong beliefs about their illness being as threatening as those in the advanced stages (CKD stages 4-5) or with  $\geq 8$  symptoms. The patients who experienced more symptoms or had more advanced CKD expressed less illness coherence than those experiencing fewer symptoms or in earlier CKD stages. Negative illness perceptions, i.e. experiencing more symptoms and perceiving the illness as more threatening was associated with an impaired HRQoL and also with mainly evasive, fatalistic, emotive and supportant coping styles. A substantial part of the patient responses referred to behavioural and psychological attributions as contributory causes to their CKD. Leg cramps, stiff/sore joints, dry skin and impaired sexual desire/ability were the most commonly reported symptoms in earlier CKD stages. Fatigue, lack of energy, leg cramps and thirst were the most common symptoms in the advanced disease stages. An uncertainty assessing symptoms attributed to CKD was indicated, especially in earlier CKD stages. **Study II** had a cross-sectional design with 535 patients across different stages of renal insufficiency (CKD stages 2–5) up to initiation of dialysis treatment, and 55 controls assessed for HRQoL through the SF-36 questionnaire together with biomarkers. All HRQoL dimensions deteriorated significantly with impaired kidney function, with the lowest scores in those with kidney failure (CKD 5). The largest differences between the patient groups were seen within physical health. The smallest disparities were seen in bodily pain and mental health. Patients in earlier CKD stages showed significantly decreased HRQoL compared to matched controls. Patients in CKD 5 demonstrated significantly deteriorated scores also in mental health compared to those in CKD 4. Glomerular filtration rate  $< 45$  ml/min/1.73 m<sup>2</sup>, age  $\geq 61$  years, cardiovascular disease (CVD), diabetes, C-reactive protein (CRP)  $\geq 5$  mg/L, haemoglobin  $\leq 110$  g/L, p-albumin  $\leq 35$  g/L and overweight were associated with impaired HRQoL. CRP and CVD emerged as primary predictors of impaired HRQoL, followed by reduced GFR and diabetes.

In renal care, increased understanding of illness perceptions and HRQoL are important assignments, since they interrelate and also have an impact on the patients' coping and health behaviour. Skilled attention to the patients' illness perceptions and HRQoL may enable health care providers to identify patients at risk for sub-optimal self-management and/or impaired HRQoL, identify and focus on relevant problems as well as supporting healthy behaviour, self-management and self-care. There is a need to further evaluate effective strategies to enhance illness perceptions and HRQoL in CKD patients such as educational interventions, programmes for improved physical activity and - especially in advanced CKD - proper psychosocial support. The findings also indicate that renal care may benefit from a more comprehensive approach, including increased attention to health promoting interventions regarding risk factors and comorbid conditions.

**Keywords:** Chronic kidney disease, illness perceptions/representations, Health-related quality of life, health behaviour, self-management, nursing, comorbidity.