Effect of dialysis initiation on health-related quality of life and symptoms in older patients

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In recent decades we have witnessed tremendous advancements in medicine contributing to treatment improvements and prolonged survival. In addition, there is a trend that has put more emphasis on individualized care, patient-reported outcomes, and quality of life. Thus, there is an upsurge of studies reporting on health-related quality of life (HRQoL) and symptoms in the chronic kidney disease (CKD) population over the past two decades. Nevertheless, most of this research is of cross-sectional design and there is still a lack of data on the longitudinal changes in HRQoL related to CKD progression, especially pertaining to the commencement of dialysis treatment.

The number of patients over 65 years with CKD has increased globally, driven mainly by the increasing prevalence of diabetes and hypertension. These persons are often not eligible for kidney transplantation and they remain on dialysis indefinitely. Therefore, improving HRQoL and lowering symptom burden on dialysis might be more important than increasing longevity in this population. The decline in HRQoL and symptoms in CKD are associated with increased morbidity and mortality both in dialysis and pre-dialysis patients. These outcomes remain underrecognized and underestimated in daily healthcare since certain symptoms or needs are difficult to address. Also, to adequately interpret HRQoL outcomes for an individual CKD patient, information is needed on HRQoL degree and patterns in larger groups of patients with kidney failure. Longitudinal data about HRQoL and symptoms in CKD are also lacking and little is known about the effect of dialysis on HRQoL and symptoms in older individuals.

The EQUAL study

The European Quality study on treatment in advanced CKD (EQUAL study) is a prospective multicenter cohort study that investigated the evolution of HRQoL before and after starting dialysis in older patients with kidney failure from six European countries. It included over 1,700 patients over 65 years of age with CKD from their first drop in eGFR below 20 mL/min and followed until death, transplantation, loss to follow-up, or end of follow-up. The patients filled out the Dialysis Symptom Index (DSI) and 36-item Short Form Survey (SF-36) every 3 to 6 months to assess symptom burden, symptom severity, and mental and physical HRQoL. Through DSI, patients indicated the presence of 30 symptoms in the past month, resulting in a total sum score for symptom numbers ranging from 0 to 30. They also rated symptom burden on a five-point Likert scale, ranging from one for "not at all" to five for "very much" burdensome, resulting in an overall symptom burden score ranging from zero to 150, with higher scores indicating a larger burden. As for HRQoL, the SF-36 provides a mental component summary (MCS) and a physical component summary (PCS). Scores can range from 0 to 100, with higher scores indicating a better HRQoL. Out of 590 patients who started dialysis during the follow-up, 457 who filled questionnaires at least once during the year before or after dialysis, and every 3-6 months during the follow-up were included in the analysis using the linear mixed effect models.

The participants were predominantly male (75%) with an average age of 76 years. The results showed that the number of symptoms, symptom burden, and symptom severity worsened considerably before and stabilized after dialysis initiation. The number of symptoms increased by 4 in
the year before dialysis initiation, and the symptom burden increased by 13. In the year after dialysis initiation, the symptom number decreased by 1 and the symptom burden by 6. The most prevalent and most burdening symptoms were “fatigue”, “decreased interest in sex”, and “difficulty becoming sexually aroused”, of which only “fatigue” somewhat improved after dialysis initiation. The gastrointestinal symptoms worsened in the year before the initiation of dialysis, and then stabilized, even slightly improved, in the subsequent year. Leg swelling improved in the year after the initiation of dialysis, which was expected due to the effect of dialysis on fluid overload. However, certain symptoms, such as “itching” and “muscle cramps”, did not change much after the initiation of dialysis, due to their multifactorial nature. Dialysis therapy itself can also promote new symptoms such as “worrying”, which increased considerably in the year before the initiation of dialysis, probably due to fear of the impending treatment, but subsided afterward.

![Figure 1. Symptom number and symptom burden in the year before and after starting dialysis in older patients](image)

Previous studies in different patient populations showed minimal clinically important changes in mental health. In the EQUAL study, both MCS and PCS decreased during the year preceding dialysis. In the year following dialysis, MCS improved, but PCS continued to decline, although at a slower rate.
This analysis within the EQUAL study is the first longitudinal assessment of HRQoL and symptoms in older dialysis patients. Using linear mixed-effects models helped to deal with the missing values, which often represents a challenge in studies based on questionnaires. However, questionnaires were only available for 77% of all EQUAL dialysis patients, and there was no comparison with patients on conservative care.

The results suggest that the mental and physical components of HRQoL significantly declined in the year before commencing dialysis, but this trend stabilized after dialysis initiation. Nevertheless, they did not fully improve in the year after the initiation of dialysis. These findings may be useful in preparing older kidney failure patients starting dialysis on what to expect in terms of HRQoL.

Key points

1. In older ≥65y patients starting dialysis, HRQoL and symptom burden deteriorated in the year before, but stabilized in the year after the start of dialysis.
2. Individual symptom patterns vary. The most burdensome symptoms are fatigue, decreased interest in sex, and difficulty becoming sexually aroused.
3. These results may inform patients on what to expect in terms of change in HRQoL and symptom burden.
Further reading


