

Appendix S1.

Additional, detailed comments taken from the questionnaire study

"Once you have overcome the renal disease and the resulting dialysis dependency, new health problems will occur." Additionally: "Due to diabetes, I lost my little finger and my right big toe. This is much worse than the renal disease or the dialysis itself."

We also noticed the difficulties of patients to accept a given diagnosis. "You can't imagine how many physicians I visited. It is frustrating not to know the reason for my dreadful pruritus. I can hardly trust them anymore"

Strong limitations in everyday life were mentioned such as reductions in the amount of fluid intake, high dose of daily medication and difficulties in grocery shopping (e.g. "It is difficult to carry the shopping bag, this takes a very long time due to my reduced health"). All patients reported exhaustion and fatigue as limitations an HD patient has to cope with in daily life. Also difficulties in cooking and taking care of the household were stated. Thus it also became apparent that everyday worries should be more included in patient-oriented questionnaires: "Family leave requires strong organisation, and even cooking! You always have to take into account dietary restrictions and so on ...". Single patients reported the fear to become a burden for their family. Only one of the participating HD patients was still able to work and was still employed. "Nearly nobody is able to work. Everybody has strong limitations in everyday

life! Many of these questions and the given answers (KDQOL) don't really reflect our daily situation."

"My life went very well, except of my disease. My husband always supported me. This is why I thought it would be stupid to think about suicide. But when pruritus becomes worse, I can imagine that some patients may think about it. So when you are really bad off and kind of crazy due to pruritus, this could really make you think about suicide." Patients' statements about social contacts and impairments were also alerting: "When pruritus was worst, I had to cancel visits and any social activity."

When asked how to deal with the time-consuming aspect of dialysis, one HD patient stated annoyed: "If you don't take the time needed for dialysis, you don't even have to go there – but then you can just wait and watch yourself dying." So patients suggested avoiding this question in the questionnaire. When they were asked if they expect their health condition to worsen, this question was criticised by HD patients: "If one would expect this, no one would take upon himself an exhausting thing like dialysis." Regarding the question on how to improve the questionnaire, one patient stated he would appreciate a question on comorbidities (e.g. pain and spasms).

"It annoys me that there are so many repetitive questions." Others stated some of the questions to be irrelevant. "Ask a patient with chronic kidney disease if he is fine – he will never say he is! This disease is a judgement like a slap in the face!"