

## SHORT COMMUNICATION

### Qualitative Interviews on Chronic Pruritus in Haemodialysis Patients

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In 2010, over 384,000 patients received haemodialysis (HD) in the U.S. (1), and in Germany about 63,300 patients per year depend on HD (2). It is estimated that worldwide more than 2 million people suffer from end-stage renal disease (ESRD) that requires HD. It is predicted that this number will continue to increase, making ESRD a significant public health issue (3). Chronic pruritus (CP) is a frequent but often overlooked symptom in HD (4) that affects patients' well-being and reduces the quality of life (QoL) (5–8). A few existing studies suggest CP to occur in 20–75% of HD patients (6, 7, 9) but there are strong variations according to country and dialysis facility (9). Although HD patients already suffer from strong limitations in their everyday life and are often affected by depression (9, 10), qualitative data on fears/burdens, needs and healthcare situation in HD patients suffering from CP are sparse. In a previous study we already showed the difficulties CP patients have in handling and coping with this symptom (11). Here we investigate CP patients with and without HD concerning the perception of CP and patients' special needs: how do these patients feel, what is important for them and how do they perceive the symptom of CP?

#### MATERIAL AND METHODS

We conducted semi-structured interviews using open-ended questions in patients who had consulted the itch clinic at the University Hospital Heidelberg between November 2012 and January 2013. The study was conducted in accordance with the World Medical Association's Declaration of Helsinki. Fourteen patients suffering from CP took part in the study. Eight of them were HD patients, 6 patients suffered from CP caused by dermatoses or CP of mixed (non-systemic) origin without any comorbidity. Six patients were women and 8 were men. The age range was 28–88 years. The mean age was 67.4 years. One interview lasted on average 1–2 h.

Prior to the interview we asked all patients to fill in questionnaires that are used in nephrological and dermatological practice: (i) The KDQOL-SF™ (Kidney Disease Quality of Life Short Form), a special instrument to measure QoL in patients with present kidney disease (12). (ii) The ItchyQoL, a pruritus-specific QoL-questionnaire, which is validated in the German language (13). All of the patients completed the questionnaires. However, patients without HD/ESRD did not answer the questions concerning HD or kidney disease. Additionally, patients were asked open questions regarding their QoL, living/health conditions and problems/needs they receive due to their kidney disease and CP.

To evaluate the interviews we used qualitative deductive content analysis. To structure the interview situation, an interview guideline allowing narrative form was used (14).

#### RESULTS

The most important statements of the HD patients concerned 6 main points: 1. additional health problems and comorbidities; 2. Sleep disruption; 3. Fatigue; 4. Suicidal ideation; 5. Time-consuming aspect of HD; and 6. Interview forms are too long (Appendix S1<sup>1</sup>). These statements demonstrate the impact of HD patients' comorbidities and resulting (secondary) diseases. HD patients expressed a high influence on QoL that is not only caused by dialysis but also by CP: "It is disastrous – additionally to the burden of dialysis – if you also suffer from pruritus." Moreover: "Pruritus frequently impaired my QoL; from the moment it started, my QoL always dwindled." (Appendix S1<sup>1</sup>). There were further interesting comments showing attitudes and needs of patients. "Pruritus is something really terrifying; this is at least as bad as pain".

Five HD patients also commented that a question on sleep should be added to the questionnaire as sleep is often impaired due to CP (Appendix S1<sup>1</sup>).

Another comment pointed to the need to address suicidal thoughts when talking about pruritus (Appendix S1<sup>1</sup>).

Half of the interviewees claimed the KDQOL to be too long and redundant in several questions. Measuring the time to fill in the KDQOL showed an average duration of 25 min (Appendix S1<sup>1</sup>).

#### DISCUSSION

Qualitative research has received increasing attention and importance in the medical field because it gives a deeper insight in patients, concerning aspects that cannot be measured such as subjective illness perception (11, 14). It does not seek empirical but theoretical generalisability, therefore there is no requirement to ensure that the sample is of sufficient size to provide estimates. Usually qualitative samples are small in size, as the type of information that qualitative studies yield is rich in detail. After reaching the point of diminishing return, increasing the sample size no longer contributes new evidence (1). This qualitative study adds new and important details about daily life, wellbeing and needs of HD patients suffering from

<sup>1</sup><http://www.medicaljournals.se/acta/content/?doi=10.2340/00015555-1823>

CP. They face great limitations in every-day-life such as restrictions in cooking, food selection, exhaustion and fatigue (the latter in daily life but also during the course of HD). These limitations were not reported by CP patients without HD and also not in our previous interviews (11). However, concerning family life and social contacts both groups of CP patients (with and without HD) share the same impairment.

The interviews show that the general health condition is more impaired and comorbidities play a greater role leading to a higher burden of disease in CP patients with HD. For future studies, we suggest to address this issue by using for example the Charlson Comorbidity Index (15).

HD patients reported to frequently suffer from concentration disorders, indisposition and impairments due to sleep disturbances among other things. Considering this, the frequently mentioned redundancy of questions by HD patients should not be overrated in this study. However, the KDOQL was described as being too long which is comprehensible because it took single patients up to 40 min to fill it out. To measure pruritus-related QoL in HD patients with CP we suggest to favour the ItchyQoL and the SF-12 questionnaire (not-dialysis specific QoL-instrument) if there are time limitations in future studies. Previous studies showed a significant association between CP and psychosomatic cofactors, poorer sleep quality and impaired QoL in HD patients (5). As depression is increased in CP patients and in HD patients (5–8), we assumed depressive disorders to be increased in HD patients with CP. We recognised a high amount of allusions concerning depressive feelings in these interviews. For future studies in HD patients, the HADS-questionnaire (Hospital Anxiety and Depression Scale) (16) could cover the patient's anxiety and psychosocial status.

As in our previous research (11), HD patients expressed their distrust in a given diagnosis which was remarkable as they have been suffering from ESRD for years. As non-adherence is a general problem in patients with a chronic disease, the patients' stated distrust in their given diagnosis and treatment should be taken seriously. In summary, the findings of these interviews may help to better identify patient-oriented outcome measures when investigating CP in patients on HD.

*The authors declare no conflict of interest.*

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