

## Quality of life on Tolvaptan.

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### Introduction

In the United Kingdom ADPKD affects approximately 70,000 people<sup>1</sup>. 70% will progress to end stage renal disease<sup>2</sup>. Tolvaptan is the only licenced medicine that has been shown to improve the rate of decline of renal function in ADPKD patients. In 2015 NICE licenced Tolvaptan for use in CKD stages two and three who show a rapid decline in kidney function<sup>3</sup>. Tolvaptan has significant side effects which can affect patients' quality of life. These include thirst, polyuria, nocturia, dry mouth and dizziness. Tolvaptan can also cause liver dysfunction. In the Tempo 3:4 there was a 23% discontinuation rate for patients taking Tolvaptan, 15.4% of this was due to side effects<sup>4</sup>. Little is known about the quality of life of the ADPKD population taking Tolvaptan.

We aimed to assess the feasibility of using a questionnaire to compare the quality of life of patients taking Tolvaptan with those who had discontinued the treatment.

### Methodology

A qualitative approach was taken for this audit. The patients sampled are those who are currently, or have been, prescribed Tolvaptan in our unit. These patients were approached to complete a validated international quality of life questionnaire (EQ-5D-3L)<sup>5-6</sup>. This questionnaire covered pain, anxiety, ability to complete usual activities and overall self-perceived health rating. We recorded maximum dosage and duration on Tolvaptan. A similar process was completed for those patients no longer taking Tolvaptan and reason for discontinuation documented. We also recorded current GFR and GFR at commencement or discontinuation of treatment and frequency of monitoring liver function.

### Results

Eleven patients taking Tolvaptan and five that had discontinued treatment completed the questionnaire. The populations were comparable in terms of gender and age. The majority of patients in both groups achieved the maximum dose. The mean overall health self-rating for the Tolvaptan group was 79/100 and 68/100 for the discontinued group. There was no significant difference between the two groups (P=0.9). Three patients stopped tolvaptan due to intolerable side effects. The mean reduction in eGFR in the Tolvaptan group was 22.5% compared with 35% in the discontinued group. All patients had their liver function tested every three months.

### Discussion

It is feasible and easy to use the quality of life questionnaire EQ-5D-3L to assess the impact of the side effect profile of Tolvaptan in the ADPKD population in a clinic setting. In future performing questionnaires in a larger number of patients at intervals may assess for change in quality of life. An alternative questionnaire may be better to capture the subtle differences in the symptoms of Tolvaptan.

### Conclusion

We found that there was no difference in the quality of life between those taking Tolvaptan and those who had discontinued Tolvaptan.