

# Current Management of Autosomal Dominant Polycystic Kidney Disease (ADPKD) UK Patients' and Carers' Experiences



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## Introduction

ADPKD is a chronic progressive systemic condition and the most commonly inherited kidney disease. At the time of this research there was no licensed treatment available to address the underlying condition of ADPKD. Management is restricted to symptomatic control, including widespread antihypertensive medication, antibiotics to deal with infections arising, analgesics to help alleviate the pain and RRT. In addition, medical emergencies, especially with kidney and liver cyst complications, have to be dealt with ad hoc, often involving hospitalisation. In the absence of approved ADPKD PROMS or guidelines, a survey was undertaken in the UK to assess the real impact of the condition on patients and their families, and the degree of success of current management.

## Methods

The survey was compiled via QuestionPro and distributed to 2,700 people on the PKD Charity's database plus promoted via various social networks. It ran between 1.11.2014 and 31.12.2014. A total of 651 individuals responded of whom 513 were ADPKD patients, and 138 relatives/carers. Of the patients, 65% of respondents were female and 35% male, with ages ranging from 20-24 years to 65 years or older.



Polycystic vs normal kidney



Word cloud showing impact of ADPKD on UK patients

*"I don't think my drugs deal adequately with the type of pain that I have, for example they don't work well in dealing with the chronic pain that interferes with my sleep"*

*"I find that my renal consultant has a hard time understanding the chronic and acute pain I get due to ADPKD. It is often brushed aside"*

## Not Just Pain

### ADPKD impacts on all areas of life:

- Over 90% admitted to feelings of anxiety, sadness, guilt, inability to make decisions, lack of concentration, loss of self-confidence and hopelessness.
- Over two-thirds reported impact on overall family life, with 54% reporting limitations on normal social activities with family, friends and neighbours.
- Nearly half reported impact on their sex life, with frequent references to marriage difficulties and breakdowns.
- A quarter were concerned about impact on their career, with 35% having already made career sacrifices, due to physical limitations, pain and general debility.

## Conclusion

Whilst there are undoubted limitations in such patient-led research, this survey highlighted some consistent trends in patient experiences of ADPKD management. Patients certainly need better symptomatic control, advice and support. What they also need is better recognition

## Results

### General Health:

- Reported as being 'poor' or 'fair' by 35% of patients.
- Wide range of ongoing signs and symptoms, including hypertension, pain, tiredness, fatigue, leg cramps, infections and enlarged abdomens.

### Severity and Impact:

- 47% reported suffering acute severe pain at least once a month, 11% on a daily basis.
- 30% reported suffering 'extreme', 'severe' or 'moderate' chronic pain.
- 41% said pain interfered with their normal daily life 'extremely', 'a lot' or 'moderately', with additional 28% reporting a slight influence.

### Efficacy of Management:

- 42% reported receiving inadequate pain relief, despite widespread analgesic prescriptions
- Frequent verbatim assertions that medical professionals totally underestimated the pain and its impact

- 19% of responding carers had had to leave their employment and 21% had had to make career sacrifices.
- Loss of earnings of between £10,000 and £100,000 frequently cited.

## The Future

- 73% of patients were 'extremely', 'very much' or 'moderately' bothered by the future of children who inherit ADPKD.
- 35% of carers had both a spouse/partner and a child with ADPKD, but only 30% of patients and 20% of carers had been offered genetic counselling or family planning advice.

## The Bottom Line

- Overall 45% of patients rated current healthcare approaches, as fair, poor or very poor in managing their ADPKD.

by healthcare professionals in both secondary and primary care of the immense and diverse impact of the condition.

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