Dietary Management, Lifestyle Adaptations, Psychological & Social Support

Patient Working Group

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Disclosure of Interests

No relevant disclosures
Physical, Biological & Psychosocial Burden
Addressing patient confusion:

– What changes should I make to my lifestyle now? How can I help myself?
– I have to drink ‘water’ but why and how much? Does the amount vary by gender, size? How do I know if drinking water works?
– If I live in Africa, how can I afford or even get enough water to drink? What about water quality variability? Or fluoride content?
– I’ve read about kidney patient diets on the web:
  • Do I have to give up protein and bananas?
  • I’ve read that caffeine is ‘bad’ – should I stop drinking tea and coffee?
– Should I take – or avoid – vitamin supplements?
– I’m asymptomatic:
  • How do I know if these lifestyle changes will have any effect over my lifetime?
  • How can I stay motivated every day?
– What if I stray from my ‘strict PKD diet’? Am I making things worse?
Psychological Help

Living with a life-threatening incurable disease:

– Diagnosed and asymptomatic:
  • Fear of the future: progression variability/will I die young?
  • What about my career and family hopes?
  • Where can I find help to relieve stress and anxiety?

– Slow deterioration of quality of life:
  • Lack of energy affecting work, home and social life
  • Dealing with periods of debilitating illness and pain
  • Dialysis/transplantation while still relatively young

– Massive kidneys and liver size:
  • Clothing challenges, body image, feeling bloated/fat
  • Being thought pregnant or obese
  • Impact on relationships and sexuality
No more bungee-jumping:

– Will my favourite hobby make things worse?
– I’ve been told to avoid ‘contact sports’ – what are these?
– What could I do that might improve my physical condition?
As frightening as PKD for some patients:

– Will the same PKD lifestyle modifications help with PLD?

– Impact on women in particular:
  • Contraception advice
  • Post-menopausal advice
Healthcare Professionals (HCPs):
- Variability owing to ignorance, geography etc
- No Guidelines

Internet and family:
- Accuracy/consistency
- Frightening

Support groups:
- Developed world only
- Cultural nuances
- Under-funded
Integrated Management of ADPKD

Co-ordinated/inter-disciplinary care:
• PKD is systemic: it’s more than a ‘kidney’ disease.
• Patients need clear guidance about management, eg:
  – Frequency of monitoring by HCPs
  – Self-management (weight, BP etc)
• What can be learned/applied from management of other complex chronic conditions?
• Specialised Centres of Excellence?
  – Co-designed with patients
  – Benefits to patients and payers
  – A human right?
If presumed to improve outcomes:

- What should be included?
- Global working group?
- What are next steps?