

Counseling and Diagnostic Implications

Patient Working Group

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Disclosure of Interests

No relevant disclosures

KDIGO

ADPKD treatment and counseling challenges for doctors / nephrologists

- If diagnosed at 20, patient might reach ESRD:
 - In <10 years
 - 30-40 years (average)
 - Never
- Known impact of lifestyle choices is limited
 - Unlike with diabetes or hypertension
- Rapid increase in knowledge and potential treatments decreases certainty that future outcomes will mirror the past
 - There is a case to be made for increased hope, but how much?

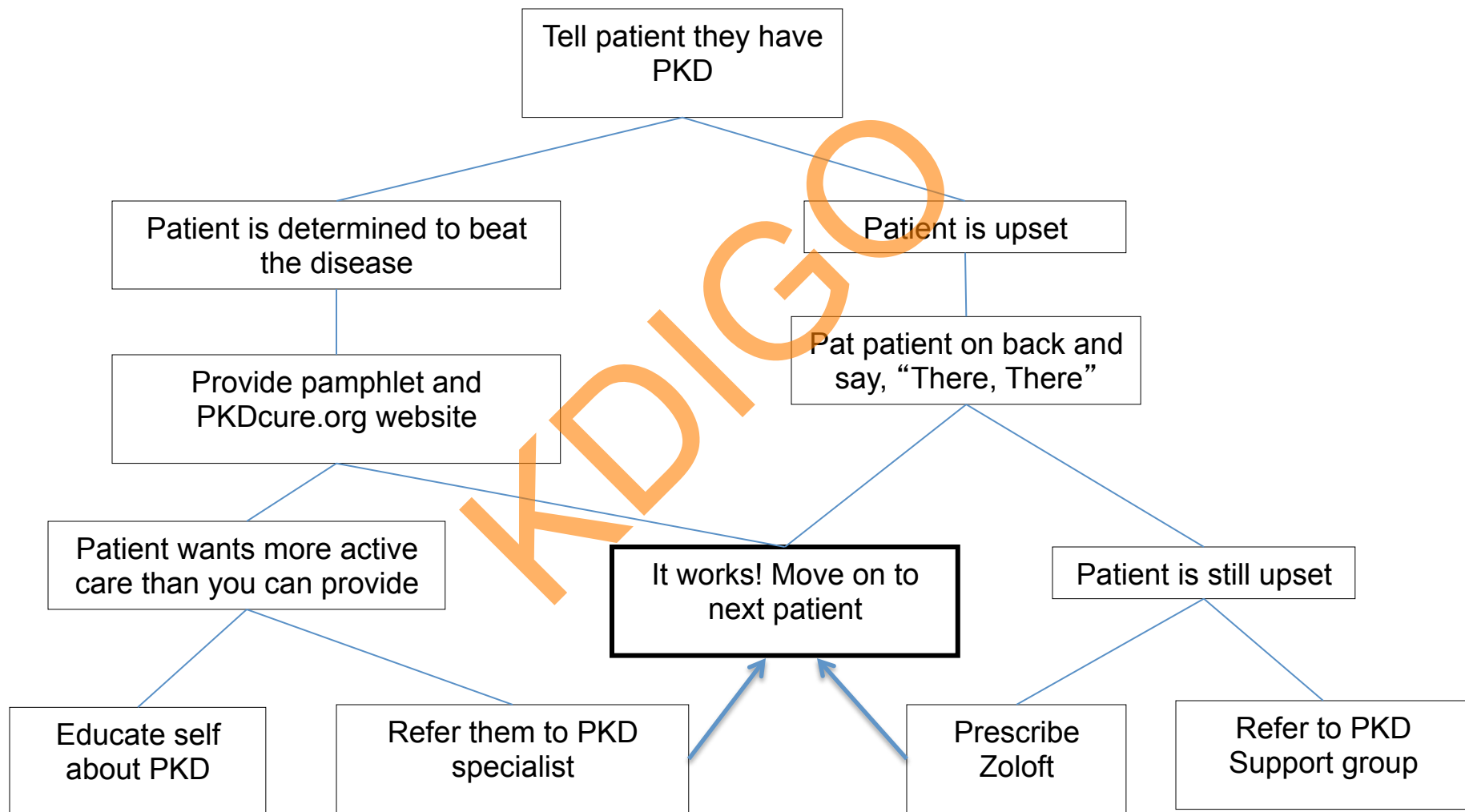
When you consider these major factors, how can patients world-wide expect consistent treatment and counseling from their doctor?

One area we will explore is the potential benefit and content of checklists for doctors and patients



The “IF / THEN / ELSE” approach

- not recommended



Experiences at first diagnosis

- If the patient has PKD in their family, they may be prepared for the diagnosis, but it will be devastating nonetheless
 - They will relate their condition to older relatives who have suffered and perhaps passed away early from PKD
 - Feelings of hopelessness, resignation, depression are common
- If the patient does not have PKD in their family (mutation), this will likely be the first time they will confront their mortality
 - Confusion, panic, desperate seeking of advice should be expected, both immediately and later
 - Denial is common, and not in the patient's best interest
- Patients will have a large number of informational needs
 - Family planning
 - Nutrition & Exercise
 - Medication
 - Financial (health and life insurance, career, longevity-related decisions)
 - Sexuality concerns (physical and emotional)
 - Health outcome scenarios
 - Dialysis/transplant
 - Related conditions such as aneurysms, blood pressure effects/stroke/vascular, PLD, etc



First Diagnosis

1. What should a doctor tell or give to a patient at first diagnosis?
 - What reactions should the doctor be prepared for?
 - Would checklists be helpful? Content?
 - Side topic: Should the PKD patient be classified differently from the current CKD classification by eGFR stage?

Family Planning

2. What are all the issues related to family planning decisions?
 - Consider ethical, moral, legal, financial, and religious perspectives
 - Include pregnancy: enlarging uterus, BP control and obstetric considerations during term

Pain Management

3. What is the best treatment plan (in all stages) for pain management?
- Exercises
 - Meditation / Relaxation techniques
 - Over the Counter medications
 - “Natural” remedies
 - Prescription Medication
 - Surgery
 - etc



Children

4. How and when do I talk to my children about PKD?
 - When should they be tested?
 - What do I tell them to do lifestyle-wise?
 - What are the impacts to adolescent quality of life?
 - PKD discussions with unaffected family members?
 - Side topic: Should a kidney growth chart for pediatrics be created?

Caution is advised in handling the screening of children <18
that in some countries is not advised if not illegal



Patient Financial Impacts

5. What are the possible PKD financial impacts?
- Career progress
 - Potentially reduced income
 - Life and health insurance
 - Long-term care
 - etc
- Are these impacts barriers to diagnosis and early treatment? If so, what can be done to change these?*

Frightening side-effect: Aneurysms

6. What practical advice and psychological support should be given to patients regarding aneurysm screening and follow-up?
- Screening recommended at diagnosis?
 - Criteria for follow-up screening?
 - MRI or CT?

Manifestation of other cysts

7. What should patients be told about the presence of cysts in other organs than the kidneys and liver?
 - What advice should patients be given about these cysts to reassure or allay fears of their effects?

Summary

- Questions? Comments?
- We welcome your input
- We look forward to collaborating with the other groups on areas of similar focus (aneurysms, pain mgt, PLD, etc)

