

Pain in Polycystic Kidney Disease

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Overview of the Types of Pain in PKD

- Acute or Chronic (= pain > 4-6 weeks)
- Chronic pain is very common in PKD
 - >60% of people experience chronic pain after the age of 40 years old
 - Can be severe
 - Major impact on physical and social wellbeing - data from the TEMPO 3:4 trial
 - impacts day-to-day life
 - 1 in 3 people leads to use of medications
 - 1 in 5 people leads to problems with sleep
 - 1 in 5 impacts physical activity and relationships with others

What Causes Pain in PKD?

ACUTE PAIN

CYST BLEEDING

- due to growth of blood vessels around cysts (neo-angiogenesis)
- In MRI scans, 90% of cysts contain 'blood' or 'protein' at any time
- Visible blood in the urine may be present in 1 in 2 people with

URINARY TRACT INFECTION (OR CYST INFECTION)

KIDNEY STONE

CHRONIC PAIN

KIDNEY PAIN DUE TO CYSTS

- Usually abdominal (rather than low back area)
- Different descriptions: Steady, nagging OR dull aching OR severe stabbing
- Standing, walking and sitting for a long period can cause pain
- Taking in a deep breath can sometimes worsen pain
- Pain does not relate to the kidney size

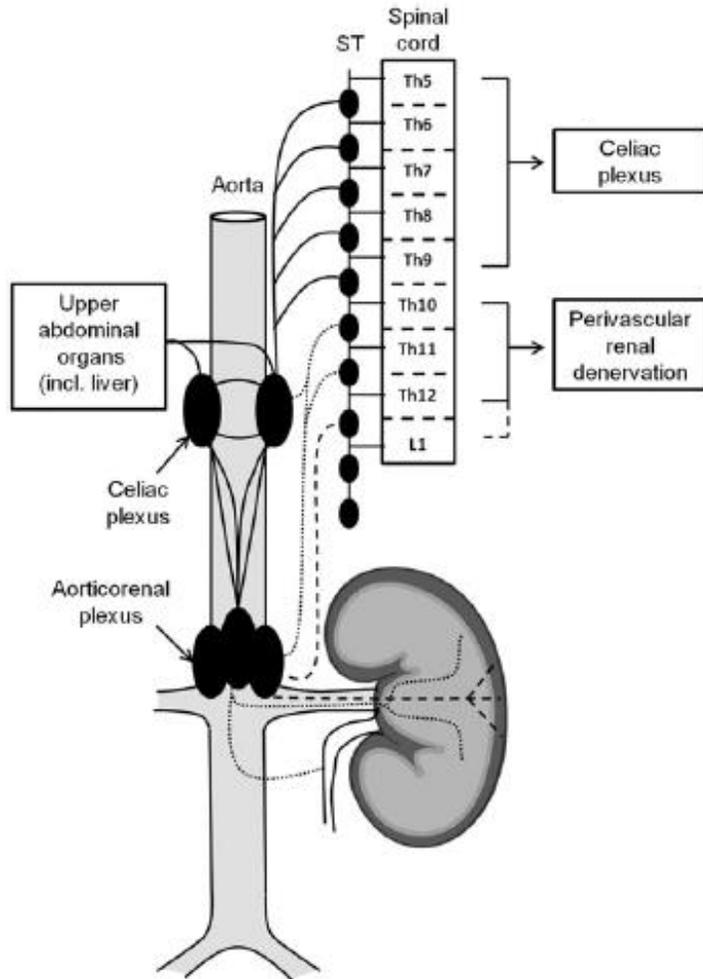
MUSCULOSKELETAL PAIN: Due to abnormal posture due to very large kidney and/or liver

PAIN NOT RELATED TO THE KIDNEY:

- Hernias
- Bowel problems: Reflux, diverticulosis
- Very large Liver (uncommon)

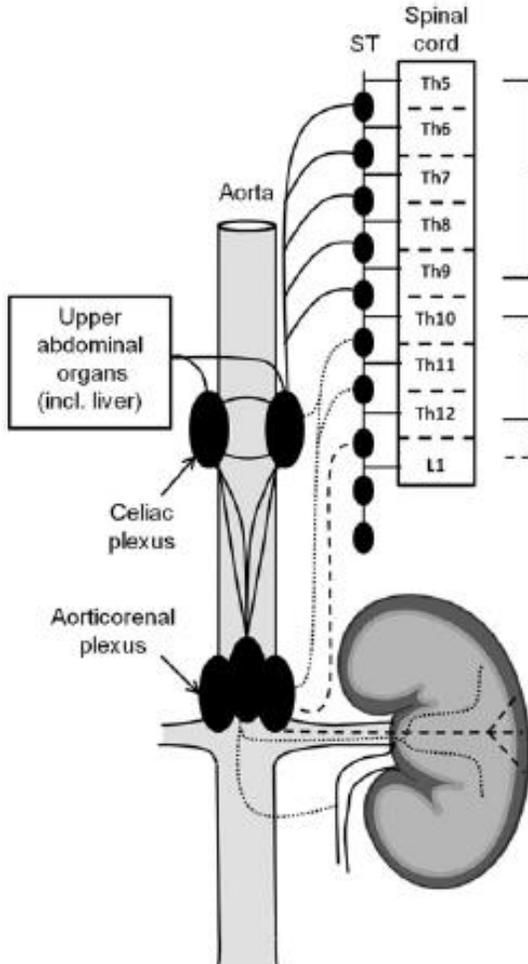
LEADS TO ANXIETY, DEPRESSION AND REDUCED QUALITY OF LIFE

Nerve supply of the Kidney



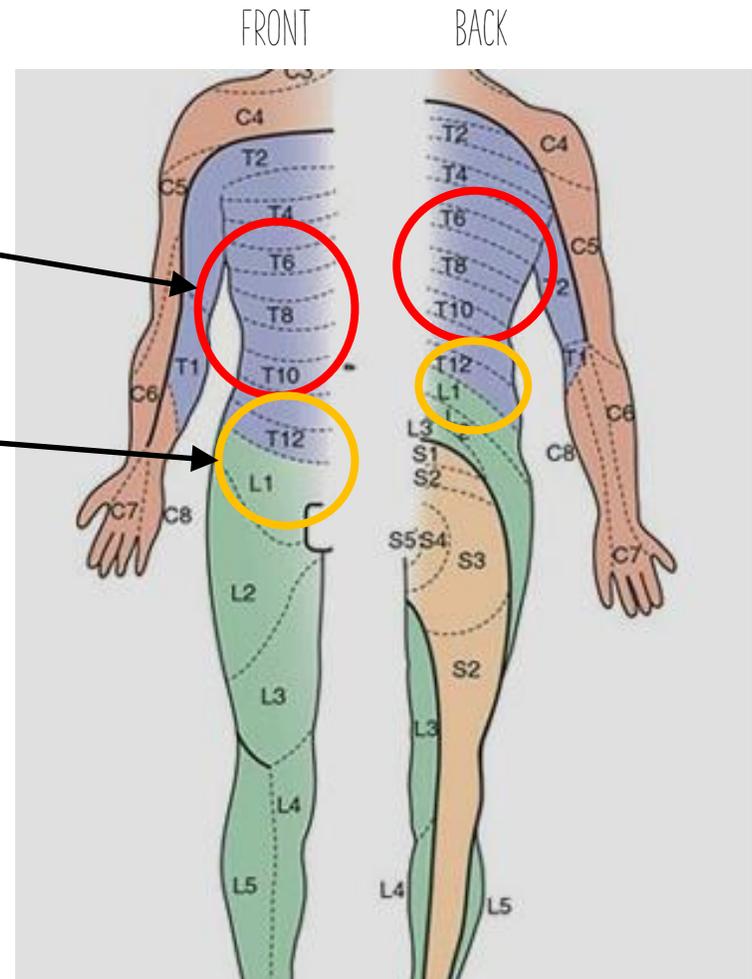
ORIGIN OF PAIN	→ NERVE →	SPINAL CORD
Upper Abdominal Organs (Kidney and Liver)	Major Splanchnic Nerve via aortic-renal and celiac plexus (solid line)	T5-T9 via celiac plexus
Kidney Tissue and Ureter	Lesser Splanchnic Nerve (dotted line)	T10-T11 via aorticorenal plexus
Kidney Capsule	Least splanchnic nerve (dashed line)	T12-L1 via aorticorenal plexus

Where might the pain be felt?



Celiac plexus

Perivascular renal denervation



How to Describe Pain to a Doctor?

- Where is the pain?
- When did the pain start?
- How often is the pain experienced?
- How severe is the pain and how do you manage it?
- Do you take any medications or any other types of treatment (prescribed or non-prescribed)?
- How does the pain affect your every-day life (sleep, work, activities)?

General Treatment Approaches for Pain

- Treatment must be individualised and tailored depending on the symptoms and situation

- Non-medication Approaches:

Physical Therapy, Massage, Ice and Heat, Alexander Technique

- Medication-Based Approaches:

World Health Organisation → 3-step analgesic ladder on fixed-dose schedule:

1st Step: Mild Pain: Paracetamol

2nd Step: Moderate Pain: Mild opioids (tramadol, oxycodone) + paracetamol

3rd Step: Severe Pain: Strong opioids (fentanyl, hydromorphone) + paracetamol

Specific Points about the WHO Plan for Chronic Pain in PKD

- Route of administration for opioids - best evidence for efficacy is transdermal application (skin)
- Balance between side-effects (vs. benefits) for opioid use:
 - Gastrointestinal side-effects: Constipation, nausea, vomiting
 - Brain function side-effects: Sedation, concentration ability, and dependency
 - Skin side-effects: Dry skin, itching
- Side-effects more often when kidney function is <30%
- 3-step approach said to be effective in majority of people with PKD (but no long-term studies)

Adjunct Medications and Approaches

- Anti-epileptics: Pregabalin and gabapentin
- Anti-depressants: Amitriptyline or nortriptyline
- Acupuncture: No studies in PKD but may benefit some

Minimally Invasive Therapies for Chronic Pain

Nerve Blocks (celiac/splanchnic)	Kidney Denervation	Transcutaneous Nerve Stimulation
<p><u>Technique</u>: Inject neurolytic agent (alcohol, phenol)</p> <p><u>Proposed Indication</u>: Intractable pain due to renal pain secondary 'compression' of surrounding tissue</p> <p><u>Evidence</u>: can be effective in other diseases (>70%) but not widely investigated in PKD</p>	<p><u>Technique</u>: Laparoscopic or catheter-based</p> <p><u>Proposed Indication</u>: Renal capsule pain</p> <p><u>Evidence</u>: limited experience and not widely investigated in PKD</p>	<p><u>Technique</u>: Apply small electrodes to skin on areas where pain occurs</p> <p><u>Proposed Indication</u>: Unknown</p> <p><u>Evidence</u>: No experience in PKD</p>

Surgical Approaches for Chronic Pain

Kidney Cyst Aspiration/Sclerotherapy/Fenestration	Nephrectomy
<p>Provide initial relief from pain, especially if there is a 'dominant' (>5cm in diameter) cyst</p> <p>But usually not long-lasting (>1-2 years) and uncertain success rate</p> <p>Hence not recommended for chronic pain</p>	<p>Last resort option in someone who is close to dialysis</p> <p>May lead to some or even complete pain</p> <p>Not without risks (bleeding, hernia, starting dialysis)</p>

Chronic Pain and Depression

- Chronic pain → 4-fold increased risk for anxiety and depression in the general population
- Use of medications for PKD reduces physical well-being
- Anxiety, depression and chronic reduces quality of life
- Depression and anxiety increases as chronic pain increases
- Therefore, treatment of depression is important as it will improve chronic pain and depressive symptoms

Conclusions

- Pain is very common problem and historically has been overlooked by nephrologists – please bring up pain with your doctor if you are experiencing it and discuss ways to manage it.
- The approaches to manage pain in PKD are specific to individual situations and will vary
- Much more research about pain in PKD is needed, especially the best approach to manage it and how to assess and ‘measure’ pain



REGISTER YOUR INTEREST!

SONG-PKD PAIN WORKSHOP

THURSDAY 1ST OCTOBER 2020

THIS WORKSHOP WILL BRING TOGETHER PATIENTS, FAMILY MEMBERS AND HEALTH PROFESSIONALS TO DISCUSS HOW TO ADDRESS AND MEASURE PAIN IN POLYCYSTIC KIDNEY DISEASE.

The workshop is for one hour and will be held online (using Zoom). All attendees, with permission, will be named as a collaborator on the final workshop report to be published. You can check the time for your timezone using the link below.

For more information and to register your interest, please visit:

<https://songinitiative.org/song-pkdpain/>

**For more information,
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Questions
