Illness perceptions in patients with chronic kidney disease

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"tell me the thoughts that surround you
- I want to look inside your head"
(Peter Sarstedt, 1969)

To explore and measure thoughts, perceptions and emotions

What do you think about your:
- health?
- disease?
- treatment?
Content:

- What is illness perception – sjukdomsuppfattning
- Study performed at renal out-patient clinic, Karolinska University Hospital
- Variations of illness perceptions in different CKD stages
- Symptoms
- Self-blame
- Self-mangement
- How nurses can help
Chronic Kidney Disease (CKD) Stages

Asymptomatic (?)

<table>
<thead>
<tr>
<th>Function Stage</th>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
<th>Stage 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>100 %</td>
<td>≥ 90 %</td>
<td>90 – 60 % Mild</td>
<td>60 – 30 % Moderate</td>
<td>30 – 15 % Severe</td>
<td>&lt; 15 % Renal failure</td>
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<tr>
<td>50 %</td>
<td></td>
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<tr>
<td>0 %</td>
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What is illness perception?

- The individual’s thoughts and emotions, forming a PICTURE of the disease and health threat*

- Influences health behaviour, coping

- Affects self-management, treatment outcomes, health-related quality of life**

* Leventhal (Common sense Model of Self-Regulation)
** Hagger & Orbell, 2003
Leventhal: ’Common Sense Model’ (CSM)
The Common-sense Model of Self-regulation of Health and Illness

Cognitive Representations of health threat
Symptoms, Timeline, Consequences, Controlability, Causal attributions, Illness coherence

1: Interpretation
Symptom perception
Social messages
Deviation from norm

2: Coping

3: Appraisal
Was my coping strategy effective?

Emotional response to health threat
Fear
Anxiety
Depression

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What’s happening? Why? What to do? How do I handle this?

Illness perception

CKD diagnose/symptoms

HRQoL

Self-management coping
Illness perception Questionnaire
IPQ-R  (Moss-Morris et al 2002)

- **Symptoms** (29)  
  *My kidney disease...*
- **Timeline**  
  *'is likely to be permanent rather than temporary'*
- **Cyclicity**  
  *'is very unpredictable'*
- **Consequenses**  
  *'is a serious condition'*
- **Illness coherence**  
  *'doesn’t make any sense to me'*
- **Personal control**  
  *‘I have the power to influence my CKD’*
- **Treatment control**  
  *‘My treatment can control my CKD’*
- **Emotional response**  
  *’when thinking about my CKD I get upset’*
- **Causal attributions**  
  *’stress was a major factor in causing my CKD’*
## Participants

CKD-stage 2-5 (not on RRT)

<table>
<thead>
<tr>
<th></th>
<th>All (N=54)</th>
<th>Mild (N=14)</th>
<th>Moderate (N=21)</th>
<th>Severe (N=19)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N (%)</td>
<td>54</td>
<td>14 (26)</td>
<td>21 (39)</td>
<td>19 (35)</td>
</tr>
<tr>
<td>Age, Md (IQR)</td>
<td>56 (43-62)</td>
<td>51 (41-59)</td>
<td>56 (43-61)</td>
<td>56 (46-64)</td>
</tr>
<tr>
<td>Females, N (%)</td>
<td>23 (42.6)</td>
<td>4 (28.6)</td>
<td>10 (47.6)</td>
<td>9 (47.4)</td>
</tr>
<tr>
<td>GFR, Md (Range)</td>
<td>46 (8-81)</td>
<td>62 (61-81)</td>
<td>51 (32-59)</td>
<td>16 (8-29)</td>
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</tbody>
</table>

### Cognitive interviews

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<tbody>
<tr>
<td>N</td>
<td>7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, Md (range)</td>
<td>37 (34-84)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Females, N</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GFR, range</td>
<td>&lt;10 - 60</td>
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Illness Perception Patterns

High scores = negative beliefs
High scores = positive beliefs

Threat of illness:
- Severe
- Unpredictable
- Evoking emotional response

*p < 0.05
High scores = negative beliefs  
High scores = positive beliefs

Threat of illness:
- Severe
- Unpredictable
- Evoking emotional response

* p < 0.05
When I think about my diabetes I regard it as long-lasting. I see the kidney disease as short-lived as it can be cured by transplantation.

My kidney disease will be short-lived.../ ...when I get the new kidney, my renal disease will be gone.
## Associations with HRQoL

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Identity /symptoms</th>
<th>Timeline</th>
<th>Consequence</th>
<th>Emotional response</th>
</tr>
</thead>
<tbody>
<tr>
<td>HRQoL (SF-36)</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Physical health</td>
<td>-.670*</td>
<td>-.312*</td>
<td>-.603*</td>
<td>-.414*</td>
</tr>
<tr>
<td>Mental health</td>
<td>-.438*</td>
<td>-.267</td>
<td>-.488*</td>
<td>-.404*</td>
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</tbody>
</table>

Negative illness perceptions correlated with ↓ HRQoL

*p < 0.05
Causal Attributions
The patients’ perceptions of factors contributing to their CKD

- Own behaviour: 37%
- Immunity: 19%
- Heredity: 16%
- Accident or chance: 28%
I have cystic kidneys, one may push the disease progression by exposing oneself to certain things, like physical overstrain.

I look back at my childhood summers. Then I got cold walking along with wet swimming trunks. I could have prevented and affected the course of the disease by not doing so.

I was so stressed at the time the disease happened. I was about to start at high school and had been such a good pupil, and now I ended up in a class with people even more ambitious and clever than me!
...there's this thing where you feel guilt in some way.../...I’ve had quite a stressful job, and I think also my dietary habits might have had an influence.

I had a row of throat infections and had to take lots of antibiotics. I think it had an influence on my immune system in the sense that I got more vulnerable to diseases, and then in combination with stress and overwork.
Most commonly reported symptoms (54 patients) | N (%)
--- | ---
Fatigue | 29 (54)
Leg cramps | 29 (54)
Lack of energy | 25 (46)
Shortness of breath/dyspnea | 25 (46)
Stiff/sore joints | 22 (41)
Dry skin | 22 (41)
Impaired sexual desire/ability | 20 (37)
Weight change | 20 (37)
Thirst | 20 (37)
Frequently reported symptoms

CKD 2-3
Symptoms (M): 4
Leg cramps, stiff/sore joints, dry skin, impaired sexual ability/desire

CKD 4-5
Symptoms (M): 13
Fatigue, lack of energy, leg cramps, thirst, itch, leg edema

Proportion of 'uncertain' symptoms (%)

<table>
<thead>
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<th>CKD 2 (n=14)</th>
<th>CKD 3 (n=21)</th>
<th>CKD 4-5 (n=19)</th>
</tr>
</thead>
<tbody>
<tr>
<td>68</td>
<td>44</td>
<td>35</td>
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I’m uncertain if some of the symptoms really have to do with my kidney disease. Like the diarrhea, it could as well be my diabetes or my medication. Also the muscular pain, I do have it quite often, but I don’t know what it is due to. If my blood sugar is high, for example, then I get muscular pain. I also have some troubles with breathing at night. But then I don’t know if it’s due to the kidneys or if it’s something else.

The shortness of breath I think could be because I’m out of condition. The cough I believe is due to my earlier tracheotomy, the headache I connect to my blood sugar, the gastritis has been around since earlier, the pain in my feet I think is due to the diabetes, my sleeping difficulties I think is due to my personality and the dry skin is because I often take a shower.
Patient stage 2-3 (mild-moderate)
No/few symptoms, often uncertain whether they related to CKD

Thoughts and emotions

My kidney disease
...does not have much effect on my life
...does not worry me
...is a condition that I have the power to influence
I have a clear picture or understanding of my condition
Patient stage 4-5 (severe)
Many symptoms, some uncertainty whether they related to CKD

Thoughts and feelings

My kidney disease
…has major consequences on my life
…doesn’t make any sense to me
…makes me anxious and depressed
The symptoms are puzzling to me
Summary and conclusions

• Illness perceptions (IP) vary with different CKD stages and with symptom burden

• Few & insidious symptoms  ➔ few cues, low awareness, uncertainty

• Severe CKD/many symptoms  ➔ more negative IP, low illness coherence (in spite of educational interventions!)

• Symptoms already at mild CKD. Uncertainty if symptoms relate to CKD  ➔ risk for poor adherence to treatment plan

• Self-blame regarding causes to CKD = common. Self-blame influence IP negatively
Illness Perceptions matter!
Assumptive risks for health behaviour and self-management

Stage 2-3 (mild-moderate)
- Symptom uncertainty
- Positive illness perceptions
- Lacking disease awareness and health related knowledge

Stage 4-5 (severe)
- Multiple symptoms, impaired health & QoL
- Negative illness perceptions
- Emotional reactions
- Deficient illness coherence, control & confidence

Underwhelmed

Overwhelmed

Insufficient self-management, life style changes and adherence to treatment regime (medication, controls, diet, weight, physical activity)
Successful treatment outcome is linked to successful self-management
Self-management is influenced by illness perceptions

How can we explore and meet illness perceptions?
How can we support self-management and help our patients to help themselves?
Increased understanding of patient’s illness perception may contribute to

<table>
<thead>
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<th>CKD 1</th>
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<th>CKD 4</th>
<th>CKD 5</th>
</tr>
</thead>
</table>

- Identifying risk for insufficient self-management
- Exploring & meeting ‘symptom-language’, misunderstandings, uncertainty, fears, maldaptive beliefs and coping/health behaviour
- Improving & tailoring support for coping and self-management
- Expand patient education programmes
- Learning to ask questions about the subjective world - and listen

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How is your life affected by the kidney disease

How long do you think your kidney disease will last

How much control do you feel that you have

Which are your thoughts about your treatment, - your medicines

How worried are you

Which are your feelings

What do you think may have caused
Summary: Nursing interventions

- **Reflective communication**: listen, explore, meet, support, guide
- **Identify** patients at risk for suboptimal self-management
- **Tailored interventions** to support healthy life style changes and self-management
- **Expand patient education programmes** to support self-management from early CKD stages and **offer support** when getting close to start RRT - Patient partnership
TACK!

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The Illness Perception Questionnaire
Website: uib.no/ipq

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