Illness Perceptions and their associations with psychosocial and clinical outcomes in advanced kidney disease (and other long-term physical health conditions)

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Co-editor British Journal of Health Psychology
Common Sense Model of Illness Perceptions (CSM)

Illness Perceptions and their association with outcomes (*depression, survival, kidney function, quality of life*)

Role of illness perceptions in other LTCs

Illness perceptions as a basis for intervention

Future directions and conclusions
Illness Perceptions and the CSM
(Leventhal et al 1980; 1984; 2003)

Model of self-regulation (monitor and adapt behaviour towards a goal)

Illness representations refer to organised beliefs surrounding an illness, following an illness threat

Organised in memory (schema), that is, a mental model of the condition

Influence by social and cultural factors

“Defines the illness experience and subsequent attempts to control the illness threat” – Illness perceptions guide coping procedures in an attempt to control the threat (i.e. IF-THEN RULES)
ILLNESS PERCEPTIONS

Identity  
Illness label and attributed symptoms

Consequences  
Perceived effects of illness

Timeline  
Chronic, acute or cyclical beliefs regarding illness duration

Control/Cure  
Controllability of the illness

Causes  
Perceived causal factors

Coherence  
Perceived understanding of the illness

CSM  
(Leventhal et al 1980; 1984; 2003)
The Common Sense Model of Self-Regulation: Meta-Analysis and Test of a Process Model

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Curtin University and University of Jyväskylä

Severine Koch and Nikos L. D. Chatzisarantis
Curtin University

Sheina Orbell
University of Essex

According to the common-sense model of self-regulation, individuals form lay representations of illnesses that guide coping procedures to manage illness threat. We meta-analyzed studies adopting the model to (a) examine the intercorrelations among illness representation dimensions, coping strategies, and illness outcomes; (b) test the sufficiency of a process model in which relations between illness representations and outcomes were mediated by coping strategies; and (c) test effects of moderators on model relations. Studies adopting the common-sense model in chronic illness ($k = 254$) were subjected to random-effects meta-analysis. The pattern of zero-order corrected correlations among illness representation dimensions (identity, consequences, timeline, perceived control, illness coherence, emotional representations), coping strategies (avoidance, cognitive reappraisal, emotion venting, problem-focused generic, problem-focused specific, seeking social support), and illness outcomes (disease state, distress, well-being, physical, role, and social functioning) was consistent with previous analyses. Meta-analytic path analyses supported a process model that included direct effects of illness representations on outcomes and indirect effects mediated by coping. Emotional representations and perceived control were consistently related to illness-related and functional outcomes via, respectively, lower and greater employment of coping strategies to deal with symptoms or manage treatment. Representations signaling threat (consequences, identity) had specific positive and negative indirect effects on outcomes through problem- and emotion-focused coping strategies. There was little evidence of moderation of model effects by study design, illness type and context, and study quality. A revised process model is proposed to guide future research which includes effects of moderators, individual differences, and beliefs about illness.
Measuring Illness Perceptions

THE ILLNESS PERCEPTION QUESTIONNAIRE:
A NEW METHOD FOR ASSESSING THE COGNITIVE REPRESENTATION OF ILLNESS

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ROB HORNE

The Brief Illness Perception Questionnaire

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\textsuperscript{b}Health Psychology Section, Department of Psychology (at Guy’s), Institute of Psychiatry, 5th floor Thomas Guy House, London Bridge, London SE1 9RT, UK
### Patient Drawings (from Petrie and Weinman 2012)

<table>
<thead>
<tr>
<th>My Heart Now Before Surgery</th>
<th>My Heart Now After Surgery</th>
<th>My Heart Now 3 Months After Surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>![Heart Drawing]</td>
<td>![Heart Drawing]</td>
<td>![Heart Drawing]</td>
</tr>
<tr>
<td>Clagged Artery</td>
<td></td>
<td>Blood Flowing freely</td>
</tr>
<tr>
<td>Very Clagged</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>My Heart Now Before Surgery</th>
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</tr>
</thead>
<tbody>
<tr>
<td>![Heart Drawing]</td>
<td>![Heart Drawing]</td>
<td>![Heart Drawing]</td>
</tr>
<tr>
<td>Bump by lump in chest</td>
<td>Too fast</td>
<td>ok</td>
</tr>
<tr>
<td></td>
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</tr>
</tbody>
</table>

**Fig 2.** Two heart surgery patients’ drawings of their hearts before and immediately after surgery and 3 months later.
74 myocardial infarction patients (MI) 
Drew pictures of their hearts 
Recovery was assessed 3 months after (self-report) 
Compared those who drew “damage” on their hearts vs. “no damage”

Those who drew damage prior to discharge reported 3 months later:

• Taking longer to return to work
• Perceived amount the heart has recovered to be less
• Great time-line perceptions (chronic beliefs)
• Less control over the heart condition
Correlational results

<table>
<thead>
<tr>
<th>Hospital data</th>
<th></th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Damage drawn (%)</td>
<td></td>
<td>.41***</td>
</tr>
<tr>
<td>(2) Peak troponin-T</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3-Month data</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>(3) Days to return to work</td>
<td>.37*</td>
<td></td>
</tr>
<tr>
<td>(4) Perceived amount heart has recovered</td>
<td>−.45***</td>
<td></td>
</tr>
<tr>
<td>(5) Perceived duration of heart condition</td>
<td>.38**</td>
<td></td>
</tr>
<tr>
<td>(6) Distress about symptoms</td>
<td>.26</td>
<td></td>
</tr>
<tr>
<td>(7) Perceived control over heart condition</td>
<td>−.33*</td>
<td></td>
</tr>
<tr>
<td>(8) Minutes spent exercising per week</td>
<td>.20</td>
<td></td>
</tr>
</tbody>
</table>

* P < .05.  
** P < .01.  
*** P < .001.

Troponin-T (cardiac enzyme) **NOT** correlated with speed of return to work (i.e. a proxy of “recovery”)

% Damage drawn and Troponin-T levels correlated
Importance of Illness Perceptions: What is the evidence in kidney patients?

- Depression
- QoL
- Adherence
- Survival
- Physical Health
- Fatigue
Illness Perceptions and survival

223 HD patients were followed up for median of 15.9 months

The median dialysis vintage was 17.6 months

49 deaths

__Treatment Control__

HR = 0.91 (0.83-0.99) p<0.05

Adjusted HR\(^a\) = 0.89 (0.80-0.99) p<0.05

\(^a\)age, serum albumin levels, blood haemoglobin levels, co-morbidity score, log-CRP, KPS<70, Kt/V and **BDI score**
Mechanism (mediator?)

Illness Representation

Health/illness behaviours (i.e. IF-THEN rules)

Outcome
Illness Perceptions in Patients on Predialysis Care: Associations With Time Until Start of Dialysis and Decline of Kidney Function

Illness perceptions and decline in kidney function (eGFR)

<table>
<thead>
<tr>
<th>Illness Perceptions</th>
<th>Model 1&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Model 2&lt;sup&gt;c&lt;/sup&gt;</th>
<th>Model 3&lt;sup&gt;d&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Additional Change,</td>
<td>Additional Change,</td>
<td>Additional Change,</td>
</tr>
<tr>
<td></td>
<td>eGFR (95% CI)</td>
<td>eGFR (95% CI)</td>
<td>eGFR (95% CI)</td>
</tr>
<tr>
<td>Timeline acute/chronic</td>
<td>-0.07 (-0.71 to 0.57)</td>
<td>-0.05 (-0.68 to 0.59)</td>
<td>-0.05 (-0.68 to 0.59)</td>
</tr>
<tr>
<td>Cyclical timeline</td>
<td>-0.63 (-1.15 to -0.12)&lt;sup&gt;*&lt;/sup&gt;</td>
<td>-0.64 (-1.16 to -0.13)&lt;sup&gt;*&lt;/sup&gt;</td>
<td>-0.64 (-1.15 to -0.13)&lt;sup&gt;*&lt;/sup&gt;</td>
</tr>
<tr>
<td>Negative consequences</td>
<td>-0.68 (-1.30 to -0.06)&lt;sup&gt;*&lt;/sup&gt;</td>
<td>-0.67 (-1.30 to -0.04)&lt;sup&gt;*&lt;/sup&gt;</td>
<td>-0.67 (-1.30 to -0.04)&lt;sup&gt;*&lt;/sup&gt;</td>
</tr>
<tr>
<td>Personal control</td>
<td>-0.64 (-1.26 to -0.03)&lt;sup&gt;*&lt;/sup&gt;</td>
<td>-0.69 (-1.31 to -0.09)&lt;sup&gt;*&lt;/sup&gt;</td>
<td>-0.70 (-1.30 to -0.09)&lt;sup&gt;*&lt;/sup&gt;</td>
</tr>
<tr>
<td>Treatment control</td>
<td>-0.46 (-1.15 to 0.23)</td>
<td>-0.33 (-1.02 to 0.37)</td>
<td>-0.33 (-1.02 to 0.36)</td>
</tr>
<tr>
<td>Illness coherence</td>
<td>-0.54 (-1.06 to -0.01)&lt;sup&gt;*&lt;/sup&gt;</td>
<td>-0.53 (-1.05 to -0.01)&lt;sup&gt;*&lt;/sup&gt;</td>
<td>-0.53 (-1.05 to -0.01)&lt;sup&gt;*&lt;/sup&gt;</td>
</tr>
<tr>
<td>Emotional response</td>
<td>-0.64 (-1.13 to -0.16)&lt;sup&gt;*&lt;/sup&gt;</td>
<td>-0.65 (-1.13 to -0.16)&lt;sup&gt;**&lt;/sup&gt;</td>
<td>-0.65 (-1.14 to -0.16)&lt;sup&gt;**&lt;/sup&gt;</td>
</tr>
<tr>
<td>Illness identity</td>
<td>-0.07 (-0.23 to 0.09)</td>
<td>-0.09 (-0.24 to 0.07)</td>
<td>-0.09 (-0.24 to 0.07)</td>
</tr>
</tbody>
</table>

eGFR = estimated glomerular filtration rate; CI = confidence interval.

<sup>*</sup><i>p < .05</i>, <sup>**</sup><i>p < .01</i>

<sup>a</sup> Scores on the Revised Illness Perception Questionnaire subscales “personal control,” “treatment control,” and “illness coherence” were recoded: higher scores indicate lower personal control, treatment control and illness coherence.

<sup>b</sup> Model 1: crude additional change of kidney function for each unit increase on the Revised Illness Perception Questionnaire subscale during predialysis care.

<sup>c</sup> Model 2: adjusted for age, sex, work status, marital status, education, primary kidney disease, time since diagnosis, cardiovascular disease, diabetes mellitus, body mass index, serum albumin, hemoglobin, and systolic and diastolic blood pressure.

<sup>d</sup> Model 3: model 2 and further adjusted for mental health.
Distinct Depression Symptom Trajectories over the First Year of Dialysis: Associations with Illness Perceptions

Joseph Chilcot, Ph.D. · Sam Norton, Ph.D. · David Wellsted, Ph.D. · Andrew Davenport, M.D., F.R.C.P. · John Firth, D.M., F.R.C.P. · Ken Farrington, M.D., F.R.C.P.

Baseline illness perceptions differences between “groups”
(control and coherence)
Class*time p=0.013
Simple slope effects
Moderate increasing p=0.024
Cyclical timeline adj OR 1.22 [1.11-1.32]**
Neg consequences adj OR 1.14 [1.05-1.23]**
Illness coherence adj OR 0.84 [0.76-0.93]**
Illness perceptions vs. representations
Longitudinally, negative (unhelpful) illness representations predicted pain, functional disability and distress.
Significantly higher mortality in those shifting from positive to negative illness representations.
Patients whose illness perceptions changed from positive to negative were found to have an increased mortality risk compared to the stable positive group \([\text{HR} = 3.2, 95\% \text{ CI: 1.2} – 8.3, p = .02]\)

adjusting for age, valve type, baseline NYHA category, 6MWT, ejection fraction, EuroSCORE, Parsonnet, PAP and general distress scores

A second model was run which adjusted for age and the following prospective factors; cardiac rehabilitation attendance, changes in NYHA score (\(\Delta\text{NYHA}\)), 6MWT (\(\Delta\text{6MWT}\)), and general distress (\(\Delta\text{HADS total score}\)) over 1-year \([\text{HR} = 3.0, 95\% \text{ CI: 1.1} – 7.8, p = .02]\)
Using the CSM as a basis for interventions?

In hospital intervention for MI led to positive changes in illness perceptions.

Faster return to work in the intervention arm compared to control.

Petrie et al., 2002
Do illness perceptions mediate treatment outcomes?
Structural relationships

Treatment period (e.g. 8 weeks)

Mediator (i.e. belief) Pre-treatment

Treatment (CBT vs. control)

Mediator (i.e. belief) Post-treatment

Outcome (symptoms 6 months)

Outcome (symptoms @baseline)
Following CBT illness perceptions significantly changed over the treatment. This change partially mediated the observed treatment effect.
Treating distress in dialysis

• Anti-depressants – limited RCT data in renal patients regarding efficacy
• Side effects – adverse events including increased QT interval

• Some RCT evidence regarding benefits of CBT in renal patients
• How to implement in routine clinical practice?
To identify ESRF specific correlates of distress in dialysis (haemodialysis and peritoneal dialysis) based on constructs outlined in the common-sense model

Health threats

Illness specific cognitions

Self-management behaviours
Illness Cognitions

Seven cross sectional studies: the distressed cognitive profile:

- Low levels of treatment efficacy (n=2)
- Perceived lack of understanding of ESRF (n=2)
- Low perceptions of personal control over ESRF (n=3)
- Believing ESRF to be unpredictable (Timeline cyclical; n=3)
- Greater perceived physical and social consequences (N=7)
- More symptoms attributed to ESRF (Identity: n=3)
### Health threats/triggers

<table>
<thead>
<tr>
<th>Acute stressors</th>
<th>Chronic stressors - change in role/loss/identity</th>
<th>Chronic stressors - health &amp; social anxiety</th>
<th>Chronic stressors - illness management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>Burden of kidney disease for self and others</td>
<td>Changes in body image - stigma associated with fistula/catheter &amp; reminder of ill health</td>
<td>Managing food &amp; thirst cravings</td>
</tr>
<tr>
<td>Gaining vascular access</td>
<td>Altered physical functioning (housework, travel, and sex)</td>
<td>Worry about kidney disease &amp; future/waiting for a transplant</td>
<td>Unseen burden</td>
</tr>
<tr>
<td>Loss of role &amp; dependence on others</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

#### Physical techniques
- Relaxation
- Exercise
- Sleep routines
- Emotional expression

#### Attentional control and cognitive processes
- Acceptance
- Mindfulness
- Cognitive restructuring
  - Recognitions of biased &/or inaccurate cognitive thinking patterns
  - Cognitive reappraisal
  - Hypothesis testing

#### Adjustment outcome targeted by altering cognitive, behavioural and physical symptoms
- Unpredictable
- Uncontrollable
- High identity
- High consequences
- Low illness coherence

#### Mental health outcomes
- Altered sleep
- Low energy
- Altered appetite
- Increased arousal

#### Interventions
- Problem solving
- Compensatory behaviours
- SMART goal setting
- Action planning
- Assertiveness skills training
- Graded exposure

#### Symptom management
- Depression
- Anxiety
- Anger
- Frustration
CO-DEVELOPED WITH PATIENTS

My sessions

Session 1: What is end-stage renal failure?

Session 2: Why do I feel distressed?

Session 3: Dealing with my negative feelings?

Session 4: Tackling unhelpful thoughts about end-stage renal failure?

Session 5: Goal setting and problem solving

Session 6: Managing difficult social relationships

Session 7: Progress recap & preparing for the future
Often people with end-stage renal failure say they feel distressed because of the challenges their health condition causes. Some of the challenges people get distressed about are listed below. Tick up to two triggers that apply to you. If you would like to write your own trigger, then choose "My own trigger", and type it in the box below. You may have more than two triggers but because you are learning new things choose the two that cause you the most distress.

1. I feel distressed when I experience physical symptoms
2. I don't like the way I look because of my end-stage renal failure
3. I am not independent anymore because of my end-stage renal failure
4. I find dialysis and the other medications that I have to take unbearable
5. I don't like having to constantly monitor what I eat and drink
6. I feel criticised by medical staff and/or family when I don't manage my end-stage renal failure well
7. My own trigger

If you chose "My own trigger" please write it in the box below. If you change your mind you will need to delete its entry from the box to remove it.

Having trouble spotting your triggers? Click here
Below are the thoughts you associate with your trigger: I find dialysis and the other medications that I have to take unbearable. Do you notice any changes to the way you think about your end-stage renal failure too because of the way you feel?

We have listed some negative thoughts that are often associated with your trigger and negative feelings. Tick up to three that you think most apply to you. If you would like to write down some of your own thoughts, then choose “My own thoughts” and type them in the box below.

**Note:** You can only select a maximum of three thoughts. If you choose my own thoughts this counts towards one of your selections.

- I never have any spare time because of my dialysis.
- People treat me differently because I am on dialysis.
- Even when I am not attending for dialysis, I am always taking medications.
- I can never tell what I am going to feel like after dialysis, it is so unpredictable.
- I have to fit in with my dialysis sessions. I have no control over my health.
- I feel worse after dialysis and after taking all of my medications. I am not sure how good they are.
- I don’t understand my end-stage renal failure enough.
- My own thoughts

I annoy people because of my end-stage renal failure
As we talked about earlier psychological distress causes changes to your body. You can sometimes experience physical symptoms.

Because your feelings effect what you think and the things you do; you can often change the way you behave too (i.e. choosing to sleep in the day instead of seeing friends). This can make your physical symptoms worse too.

Click next to see some of the common physical symptoms people experience when they feel distressed because of their trigger.

**Something to bear in mind:** The physical symptoms we list are only the physical symptoms that we know are linked to psychological distress. There might be some overlap between these and the symptoms you experience because of end-stage renal failure and dialysis.
BELOW IS YOUR PERSONAL MODEL OF PSYCHOLOGICAL DISTRESS.

It shows how your triggers kick start a series of changes in your feelings, thoughts, behaviours, and physical symptoms. Each of the boxes in your model helps you to find key areas to work on.

This website teaches you the skills you need to target each of the areas in your personal model. This will help you to break your vicious cycle of distress.

You can print a copy of your personal model of distress by pressing the print button below or ask your therapist to print you one when you next speak to them.

**Triggers**
- I find dialysis and the other medications that I have to take unbearable

**Feelings**
- Sad
- Upset
- Angry

**Physical symptoms**
- Weight loss or gain
- Fatigue/loss of energy
- Shaking
- Stomach ache/feeling sick

**Thoughts**
- I never have any spare time because of my dialysis.
- I can never tell what I am going to feel like after dialysis, it is so unpredictable.
- I annoy people because of my end-stage renal failure

**Behaviours**
- I've stopped attending regularly for dialysis.
- Sometimes I give myself a day off from managing my end-stage renal failure and I don't take my medication.
Tailored online cognitive behavioural therapy with or without therapist support calls to target psychological distress in adults receiving haemodialysis: A feasibility randomised controlled trial

Joanna L. Hudson\textsuperscript{a,} Rona Moss-Morris\textsuperscript{a,} Sam Norton\textsuperscript{a,} Federica Picariello\textsuperscript{a,} David Game\textsuperscript{b,} Amy Carroll\textsuperscript{b,} Jonathan Spencer\textsuperscript{c,} Paul McCrone\textsuperscript{c,} Matthew Hotopf\textsuperscript{c,} Lucy Yardley\textsuperscript{c,d,} Joseph Chilcott\textsuperscript{e,}f

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\textsuperscript{f} Nuffield Department of Primary Care and Health Sciences, University of Oxford, UK
Feasibility Objectives

1. Feasibility and Acceptability of Proactive Screening for Distress on Dialysis

2. Explore trial recruitment and retention rates

3. Explore adherence to online treatment sessions and therapists support calls

4. Examine change (baseline and 12 weeks follow-up) in depression, anxiety, quality of life, illness perceptions, and health service utilisation

5. Qualitatively study patients utility and acceptability perceptions
Improving Distress in Dialysis (iDiD)
Feasibility Randomised Controlled Trial

**Treatment arms:**
Therapist supported (3 x 30 min tel calls) online iDiD CBT (7 sessions)  
**vs** online iDiD CBT (7 sessions) only

**Recruitment:**
Proactive screening for distress in NHS haemodialysis units  
- IMPARTS (iPads)

**Inclusion criteria:**
Mild/Mod Severe Depression: PHQ9 (5-19)  
    AND/OR  
Mild/Mod Severe Anxiety: GAD-7 (5-14)  
18 years or more  
Basic understanding of Internet and email address
Screening:
182/410 (44%) completed the screen.
115/182 (63%) required assistance.
Main reasons for decline (N=228):
• Non-disclosure (N=77; 34%)
• Language (N=32, 14%)
• Feeling too ill (N=25, 11%)

Eligibility:
101/182 (56%) had mild to moderate distress.
9/101 (9%) = declined contact about study.
Total ineligible = 32 (32%)
• Lack of computer literacy (N=17; 17%)

Enrolment and allocation
25/60 (42%) were randomised.
Mean age: 48 (SD 12), 60% male.
Main reasons for non-consent:
• Lack of perceived need for treatment (N=15, 43%)
• Wanted face-to-face treatment (N=5, 15%)
• Not disclosed (N=5, 15%)

Analysis
23/25 (92%) were analysed at 3 months.
182 (44%) out of 410 HD patients completed the psychological distress screens. **26% found screening unacceptable.**

Psychological distress was detected in 101 (55%) patients, 60 of these met remaining inclusion criteria.

The primary reason for ineligibility was poor computer literacy (N=17, 17%).

Twenty-five patients consented and were randomised to the supported (N=18) or unsupported arm (N=7); 92% were retained at follow-up.

The supported arm showed a trend for improved quality of life. **No differences in psychological distress were observed (d=0.15)**

No trial related adverse events occurred.
“Online CBT appears feasible but only for computer literate patients who identify with the label psychological distress. A definitive trial using the current methods for psychological distress screening and online care delivery is unfeasible”
Conclusions and future directions

• Illness outcomes have measurable unique trajectories

• Illness perceptions appear to be associated with a range of outcomes/trajectories in advanced kidney disease including fatigue, depression, QoL and survival

• Evidenced also in other LTCs

• Tailored interventions that incorporate patients illness and treatment beliefs have likely utility in this setting. Need more research!

• Feasibility of delivery and acceptability remain key challenges
Thank you!

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