PATIENTS’ PERCEPTIONS OF ILLNESS and TREATMENT

Applications to Cystinosis

John Weinman

Institute of Psychiatry & Institute of Pharmaceutical Sciences
King’s College London.
OUTLINE

• INTRODUCTION TO ILLNESS and TREATMENT PERCEPTION

• KEY BACKGROUND ISSUES

• PRELIMINARY FINDINGS
  - Interview study on experience of cystinosis
  - Questionnaire studies of mood; illness and treatment perception
RESPONSE TO ILLNESS

- HUGE VARIATION between patients.

- SOME – cope well & illness may have relatively little impact (+ benefit finding)

- OTHERS – major problems & cope in ways which may exacerbate illness outcome

- WHY?
  - Not severity or type of illness
  - ?Due to patient’s perception of illness
Leventhal’s self-regulation model

1. Illness or Health Threat
   - Leads to 'Illness' Representation
2. 'Illness' Representation
   - Leads to Coping Procedure
   - Leads to Appraisal
3. Emotional Response
   - Leads to Coping Procedure
   - Leads to Appraisal
Leventhal’s self-regulation model

IF-THEN RULES

'Illness' Representation → Coping procedure

Stimulus Health Threat

Emotional Response

Coping procedure

Appraisal

Appraisal
# Beliefs about illness

## CORE BELIEFS

- **IDENTITY**: What is this?
- **CAUSE**: What caused this?
- **TIMELINE**: How long will it last?
- **CONSEQUENCES**: What will happen as a result of this?
- **CURE / CONTROL**: What will make it better?

---

**How to assess these beliefs?**
THE ILLNESS PERCEPTION QUESTIONNAIRE: A NEW METHOD FOR ASSESSING THE COGNITIVE REPRESENTATION OF ILLNESS

JOHN WEINMAN

1Unit of Psychology, United Medical and Dental Schools of Guy’s and St Thomas’s Hospitals, London Bridge, London SE1 9RT, United Kingdom

KEITH J. PETRIE and RONA MOSS-MORRIS

2Department of Psychiatry and Behavioral Science, University of Auckland School of Medicine, Auckland, New Zealand

ROB HORNE

3The John Harris Clinical Pharmacy Unit, University of Brighton, Brighton, United Kingdom

(Received 21 December, 1994; in final form 16 October, 1995)

The Illness Perception Questionnaire (IPQ) is a new method for assessing cognitive representations of illness. The IPQ is a theoretically derived measure comprising five scales that provides information about the five components that have been found to underlie the cognitive representation of illness. The five scales assess identity - the symptoms the patient associates with the illness, cause - personal ideas about aetiology, time-line - the perceived duration of the illness, consequences - expected effects and outcome and cure control - how one controls or recovers from the illness. The IPQ has a specific number of core items but allows the user to add items for particular patient groups or health threats. Data is presented supporting the reliability and validity of the IPQ scales in different chronic illness populations.

Keywords: Illness perceptions; questionnaire; reliability; validity; chronic illness; personal models.

IPQ website
http://www.uib.no/ipq/
RECENT DEVELOPMENTS

• New Assessments
  - Brief IPQ (BIPQ)
  - Patients Drawings

• Illness perception based interventions
  - for improving patient recovery
  - for improving adherence
IP INTERVENTIONS

- Recent Systematic review of 8 interventions

- Showed:
  - all IPs are modifiable
  - partic Consequences and Coherence
  - IP changes associated with other outcomes
Intervention results

• Illness perceptions change in response to the intervention in expected ways

• Relationship with outcome variables is encouraging

BUT

• Few sig. effects on medication adherence.

• NEED TO CONSIDER TREATMENT BELIEFS
Extending the self-regulation model
Self-regulation and treatment decisions: extending Leventhal’s self-regulatory model
SPECIFIC BELIEFS
Views about prescribed medication

Necessity
Beliefs about necessity of prescribed medication for maintaining health

Concerns
Arising from beliefs about potential negative effects
Beliefs about Medicines Questionnaire (BMQ)

SPECIFIC BELIEFS about medicines prescribed for a particular illness

GENERAL BELIEFS about medicines as a whole
Studies in asthma, CHD, cancer, renal dialysis, HIV/AIDS, hypertension, diabetes & CF

Low adherence

Doubts about NECESSITY

CONCERNS about potential adverse effects

Adherence issues in children and adolescents
Looking at comparable data on non-adherence in young people

- Higher rates of non-adherence in adolescents - Oral anticancer drugs (Smith et al, 1979)
  - Average (8 months – 17 yrs) 33%
  - Adolescents (11-17 yrs) 59%

- Non-adherence increase with time - Oral anticancer drugs (Tebbi et al, 1986)
  - 2 weeks 19%
  - 20 weeks 39%
  - 50 weeks 35%

Different rates of non-adherence to different parts of treatment regimen - Adolescents on diabetes treatment (Patino et al, 2005)

- Insulin and diet 49%
- Exercise 64%
- Blood glucose tests 75%
Some reasons for non-adherence in young people

**Children**
- Treatment adherence mediated through carers/parents
- Challenging behaviours
- Cognitive functioning/ability
- Forgetfulness
- Side effects

**Adolescents**
- Forgetfulness
- Side effects
- Cognitive functioning/ability
- Transition from paediatric to adult care
- Struggle to fit in with peers

**Struggle for autonomy**
- Risk taking behaviour
- Avoidance behaviour
- Behavioural problems
- Family conflicts
- Strict parental control
- Conflict between adolescent and health care providers
Common challenges in rare genetic conditions

- Access to appropriate treatments & care
  - Treatment may be expensive
  - May only be few centres in a country providing care – travel far for apptms
  - Extensive support needs from birth of the child & through to adulthood

- Dynamics of supporting families, parents & young patients
  - Extensive lifestyle changes may be needed for the whole family
  - Social isolation, difficulty finding support groups & community
  - Social stigma of hereditary disorders
  - Psychological adjustment problems, anxiety, depression, guilt & anger of both parents and children

- Challenges with adhering to different aspects of treatment regimen (diet, drug, clinical monitoring)

- Patients may struggle with autonomy & care transition phases (e.g. paediatric to adult care at 18)
1. INTERVIEW STUDY (N=12) - to explore experiences of illness and treatment.

2. QUESTIONNAIRE STUDIES
   (a) Hospital Anxiety and Depression scale (N=18)
   (b) MARS and BMQ (N=38) - to assess adherence and beliefs about treatment
INTERVIEW STUDY

- 12 patients attending adult cystinosis clinic at Guy’s Hospital.
- Questions designed to explore experience of living with cystinosis.
- Ave duration = 43 minutes (range 26-64)
- Framework Analysis (Ritchie & Spencer, 1994)
MAIN THEMES and sub-themes

1. Physical Impact
   Short stature; visual functioning; tiredness; effects of renal failure

2. Impact of cysteamine
   Breath odour; unpleasant taste; nausea

3. Impact on autonomy & social life
   Dependence on family; health hindering independence;
   Positive support from family; negative effects on social life

4. Coping strategies
   Adaptation (resilience); personal coping strategies
   Benefit finding; seeking social support
QUESTIONNAIRE STUDIES

(a) Hospital Anxiety and Depression Scale (HADS)

(14 item scale to assess Anx & Depn in patients with physical health problems).

Score range 0-21 for both

(N=18)

• Ave ANXIETY = 9.2
• Ave DEPRESSION = 7.2
### HADS in other samples

<table>
<thead>
<tr>
<th>Sample</th>
<th>Anxiety</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolescet/young adult</td>
<td>3.8</td>
<td>2.5</td>
</tr>
<tr>
<td>General population</td>
<td>5.1</td>
<td>3.4</td>
</tr>
<tr>
<td>General practice patients</td>
<td>6.2</td>
<td>3.7</td>
</tr>
<tr>
<td>Type 1 Diabetes</td>
<td>6.4</td>
<td>4.5</td>
</tr>
<tr>
<td>General medical patients</td>
<td>6.5</td>
<td>5.0</td>
</tr>
<tr>
<td>CYSTINOSIS</td>
<td>9.2</td>
<td>7.2</td>
</tr>
<tr>
<td>Psychiatric out-patients</td>
<td>11.1</td>
<td>9.3</td>
</tr>
</tbody>
</table>
Adherence and treatment beliefs

- Medication Adherence Report Scale (MARS)
  - % Non adherent (<27) = 55%
- Beliefs about Medicines
  - NECESSITY = 19.3 (max 25)
  - CONCERNS = 14.5 (max 25)
- Correlations
  - NEC/MARS = 0.438 (p = .007)
  - CON/MARS = NS
CONCLUSIONS

- All patients have their own beliefs about their illness and treatment.
- These have “logical” and direct effects on their coping and mood.
- People with Cystinosis report major psychosocial impact of physical aspects and treatment on psychosocial functioning and mood state.
- Adherence is a key issue, and many patients report low perceived need and concerns about their treatment.