Illness beliefs, responses & outcomes: Applied health psychology

Dr Val Morrison
Bangor University
Whistlestop tour

- What is health psychology
- Our thoughts on illness thoughts
- Our thoughts on the effects of illness thoughts
  - On coping
  - On behaviour
  - On others

- And ideally with some evidence to substantiate our thoughts!
What is Health Psychology?

The scientific study of psychological processes of health, illness and health care

We investigate in order to be able to describe associations; ideally over time so we can predict outcomes; if can identify predictors, then you have a target for intervention

Describe ----------- Predict ---------------- Intervene
What do Health Psychologists do?

- Provide advice on ways to manage the thoughts & emotions associated with illness and its treatment
- Help people to learn how to monitor their illness, take medication and cope with pain or other symptoms
- Identify needs of others affected by the illness
What do Health Psychologists do?

Work with the government and NHS to shape services for people with health conditions such as Diabetes, Coronary heart disease, Primary care and public health, Older people and children, Sexual health and HIV, Cancer services.
But as a starting point....

- We need to have a robust evidence base on
  - How do people think about illness?
  - How do people feel about their illness or that of other people?
  - How do they behave in response to illness?
    - Best thing is to ask them!
Rank on a scale of 1-10 in seriousness:

Arthritis
Diabetes
Heart attack
Bronchitis
Influenza
Migraine
Cancer
Asthma
Stroke
Pneumonia
Dimensions of illness

Life-threatening-not
Disabling-not
Painful-not
Controllable-not
Consequences high-low
Acute- chronic

Some people would rather die than be disabled…
Illness or Disease?

*Disease*: something of the organ, cell or tissue which denotes a physical disorder or underlying pathology

*Illness*: what the person experiences.
Common-Sense Model of Illness

Figure 9.3 The self-regulation model: the ‘common-sense model of illness’

Illness representations- Components

Identity - symptoms - presence or absence
Cause - genetics, lifestyle, stress, bad luck
Consequences - major, financial, social
Time line - acute, chronic, cyclical
Cure/control - internal, external, possible

additions in IPQ-R (2002-)
Coherence (understanding of the condition)
Treatment control (not just personal control)
Emotional impact (illness makes me scared/anxious/angry)

Lobban et al 2005 IPQS- modified for schizophrenia
### Disease Prototypes

<table>
<thead>
<tr>
<th></th>
<th>Influenza</th>
<th>AIDS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Identity</strong></td>
<td>runny nose, fever, shivery, sneezing, aching limbs</td>
<td>weight loss, swollen glands, fever, skin lesions, pneumonia</td>
</tr>
<tr>
<td><strong>Cause</strong></td>
<td>virus</td>
<td>virus</td>
</tr>
<tr>
<td><strong>Consequences</strong></td>
<td>rarely long-term or serious (except if new ‘strain”)</td>
<td>long-term ill-health, death, uncertainty</td>
</tr>
<tr>
<td><strong>Timeline</strong></td>
<td>24 hours to a week</td>
<td>Months to years</td>
</tr>
<tr>
<td><strong>Cure</strong></td>
<td>time and self-medication</td>
<td>none; multiple treatments to delay progression</td>
</tr>
<tr>
<td><strong>Type of person</strong></td>
<td>Anybody</td>
<td>High-risk groups of injecting drug users; increasingly anyone via unprotected sexual intercourse</td>
</tr>
</tbody>
</table>
### Lay perceptions of stroke

**Jones, E & Morrison V (2006)**

<table>
<thead>
<tr>
<th>Illness perceptions (max)</th>
<th>Mean (s.d.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consequences</td>
<td>(35) 28.75 (2.65)</td>
</tr>
<tr>
<td>Cure/Control</td>
<td>(25) 15.59 (2.62)</td>
</tr>
<tr>
<td>Timeline</td>
<td>(15) 11.89 (1.93)</td>
</tr>
</tbody>
</table>

**Identity Symptoms**

<table>
<thead>
<tr>
<th>Number</th>
<th>Mean (s.d.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>(19) 16.55 (3.01)</td>
</tr>
</tbody>
</table>

**Cause**

<table>
<thead>
<tr>
<th>Chance related</th>
<th>Mean (s.d.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chance related</td>
<td>(5) 2.77 (1.09)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient related</th>
<th>Mean (s.d.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient related</td>
<td>(20) 13.42 (2.60)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Environment</th>
<th>Mean (s.d.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Environment</td>
<td>(20) 8.73 (2.21)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Genetic</th>
<th>Mean (s.d.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetic</td>
<td>(5) 3.54 (1.03)</td>
</tr>
</tbody>
</table>

**Caring Appraisals**

<table>
<thead>
<tr>
<th>Work strain</th>
<th>Mean (s.d.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work strain</td>
<td>(91) 58.63 (15.29)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Work satisfaction</th>
<th>Mean (s.d.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work satisfaction</td>
<td>(42) 34.49 (5.92)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lifestyle satisfaction</th>
<th>Mean (s.d.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lifestyle satisfaction</td>
<td>(35) 20.40 (6.80)</td>
</tr>
</tbody>
</table>
Healthy vs. patient illness perceptions of cancer (Buick & Petrie 2002)

Healthy women rated:
- Breast ca patient health as poorer
- Consequences of disease worse
- Lower belief in treatment control/cure
- Longer illness timeline
- Over-estimated n of symptoms
- Over-estimated symptom severity & frequency
- Believed more in chance, internal & genetic cause
Healthy women thought that breast cancer patients would:
- Focus on their illness
- Vent emotion
- Mentally & behaviourally disengage from treatment
- Use denial
- Use alcohol
- Use religion
- Use less positive reappraisal or acceptance

(yet were the 2 most common strategies used by patients themselves)
Illness perceptions and emotional wellbeing

Hagger & Orbell (meta analysis 2003) find that psychological wellbeing (assessed on a variety of scales)

- Negatively associated with perceived consequences - .46*
- Positively associated with Control/cure .21*
- Negatively associated with Identity -.37*
- Not associated with perceived timeline
Consequences - Disruption

P3m: Yeah. And another thing, simple things like erm.. cleaning your teeth, y’know, I couldn’t, I just couldn’t fathom, get a brush and put toothpaste on..

P8m: I used to read, I used to paint, a lot and I don’t do either now…

P5m: Mmm. So, I’ve been fed up at not having, not being able to do as much as I was able to do.

Plf: I don’t want to burden [husband] with my problems… because he’s got enough to cope with as it is.

P8m: She meithers me! … She interferes…with things

Jones, Morrison & Huws (2006)
Illness Representations and outcomes

Illness representations have been shown to have direct effects on a wide range of outcomes:

seeking and using medical treatment

emotional reactions to symptoms (e.g. depression & chronic timeline, lo coherence)

engagement in self-care behaviours or treatment adherence

illness-related disability and return to work

Carer outcomes also affected
BRIEF IPQ

How much does your illness affect your life?
0 1 2 3 4 5 6 7 8 9 10 (no affect - severely)

How long do you think your illness will continue?
0 1 2 3 4 5 6 7 8 9 10 (a very short time-forever)

How much control do you feel you have over your illness?
0 1 2 3 4 5 6 7 8 9 10 (absolutely no control - extreme amount)

How much do you think your treatment can help your illness?
0 1 2 3 4 5 6 7 8 9 10 (not at all - extremely)

How much do you experience symptoms from your illness?
0 1 2 3 4 5 6 7 8 9 10 (no symptoms - many severe)

How concerned are you about your illness?
0 1 2 3 4 5 6 7 8 9 10 (not at all - extremely)

How well do you feel you understand your illness?
0 1 2 3 4 5 6 7 8 9 10 (don't - understand very clearly)

How much does your illness affect you emotionally?
0 1 2 3 4 5 6 7 8 9 10 (not at all - extremely affected)

Please list in rank-order the three most important factors that you believe caused your illness.....

Consequences- shock & attributions

When I found out I had cancer, I just couldn’t cope with the thought of having cancer, I just couldn’t get over it, I just didn’t want to have it, it was so hard to accept, me so athletic and so outgoing and I was probably going to be dead in 6 months (P5f)

Initially this person’s carer had thought:

perhaps I’d pushed her too hard, there’s always a blame factor really, (C5m)

but subsequently reported that:

... at the end of the day, I was able to accept that this (blaming of himself) really isn’t true and if it was, you can’t go back anyway, it’s done now, gone - there’s no ‘if onlys’ in our life any more, the ‘if onlys’ in our life have disappeared. (C5m)

Ingram, Morrison et al (2006)
Illness perceptions and coping

Model assumes direct causal link IRs-coping

CFS (Moss-Morris et al, 1996)
  Identity and Cure/control beliefs positively associated with active coping, support-seeking, behavioural disengagement

Stroke (Morrison et al, 1999, 2006)
  The effect of Perceived control on mood outcome or disability recovery was NOT mediated by active coping cf exercise behaviour

Hagger & Orbell (2003) meta-analysis supports control/cure -active coping; consequences - avoidance & EE coping; high identity-avoidance & EE; timeline-reappraisal
“well I’m not an expert, I just have what I have read in the papers, but I asked my husband if it could be a heart attack because he had a feeling like…. A belt around (his) chest and down the left arm”

“I’ve got this indigestion and of course my missus says “well take some of your Zantac”. So I did like, you know, but it made no difference, and they (mum in law and wife) said ‘try some lemonade’. Then her mum gave me some mints. I tried everything.”
Discrepancies

70 dyads post heart attack
Shared similar positive illness perceptions: lower disability, fewer sexual functioning difficulties, less distress, greater vitality, better adjustment than those with

Similar negative perceptions:
Conflicting perceptions
Figuera & Weinman 2003

Mother-child discrepancies in adolescents with diabetes (Urquhart-Law); mothers maximise consequences, have stronger emotional reps
When they differ....

C2f: But you see, when he’s sat in here, on his own, and thinking, he’s making himself miserable and that’s when I want him to snap out of it. But I don’t mean snap out of the chair and jump up and run out. I mean out of here [pointing to head of patient]. This is where all the trouble is with R, its not his legs, its here. He is brooding all the time.

C6m: But erm, M’s biggest problem really...she can’t motivate herself to take an interest in anything, in doing anything, y’know, if she was doing anything...knitting, for example. It would take a couple of hours, a couple of hours would go without her thinking, wouldn’t it? I can’t get her interested in anything to do.

C8f: Well, its made it more distressing because I don’t like seeing him not doing the things that he used to do, do you know what I mean?

C8f: Well, just ordinary, really, I find a lot to do but I think, it gets, it gets a bit, I don’t like him keep watching the telly all the time, I like him to go out a bit more y’know.

Treatment perceptions

Treatment representations (Horne, 1999) representations of medication lack of knowledge of usage rationale reasons for treatment adherence/non adherence (Horne, Weinman ‘99).
Perceptions of medicine as restorative, symptom relievers, or as disruptive, harmful or addictive. 
Medication beliefs, as well as illness beliefs, influence adherence
BMQ examples

SA to SD answer responses

BS1 My health, at present, depends on my medicines
BS3 My life would be impossible without my medicines
BS5 I sometimes worry about long-term effects of my medicines
BS4 Without my medicines I would be very ill
BS6 My medicines are a mystery to me
BS7 My health in the future will depend on my medicines
BS8 My medicines disrupt my life
BS11 These medicines give me unpleasant side effects
BG1 Doctors use too many medicines
BG2 People who take medicines should stop their treatment for a while every now and again
BG3 Most medicines are addictive
BG4 Natural remedies are safer than medicines
BG5 Medicines do more harm than good
Carer impact

- Burden/strain (physical/emotional)
- Social isolation, reduced support
- Depression
- Fatigue, sleep disturbance

Approx 15% experience physical or emotional problems (moreso woman carers), some studies report >50% over GHQ distress cut-offs

*All greater in carers than age matched controls (Teel & Press, 1999; Morrison, 1999)*
Deep-seated sources of stress

Feelings of **anger** (with the person for becoming ill, being born handicapped .....)
Feelings of **guilt** (that they may have directly/indirectly contributed to the situation)
Feelings of **grief** (that they have ‘lost’ who they used to have)

*Such complex feelings are difficult to voice and if suppressed can be very stressful*
Gain in caring  
(Tarlow et al, 2004 review)

Associated with
- Relationship quality
- Satisfaction with own support system
- Increased functional impairment of the recipient**
- Problem-focused coping
- Older caregiver age
- Better caregiver health

** need to feel needed?
REACH project (Tarlow 2004)

N=1185 carers in Alzheimers

Agree a lot with:

- Feel Needed 61.2%
- Enabled me to appreciate life more 58.2%
- Feel good about myself 50.3%
- Feel useful 46.2%
- Developed a more +ve attitude to life 44.1%
- Feel appreciated 41.4%
- Strengthened my rel’n’ship with others 40.9%
- Feel strong & confident 37.4%
- Feel important 28.6%
All leads to needs

- An individual’s wish to receive support with an experienced problem
- NEED is not synonymous with ‘health problem’ i.e. a person may have a disability but feel all their needs are met
- NEEDS are subjective as well as objective i.e. we may infer a need from a depression score, yet the patient may not report a need for help with mood
- Assessing need may imply there is an existing treatment/response
- A need may not disappear just because a resource has been targeted at it
  - Assessing need can however inform health & social care professionals about areas of concern to the patient
- Health professional assessment of patient need is often discrepant from patient reported need
<table>
<thead>
<tr>
<th>Most frequent Patient Needs</th>
<th>%</th>
<th>saliency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clear straight forward information</td>
<td>84</td>
<td>8.7</td>
</tr>
<tr>
<td>Open and sincere clinicians</td>
<td>82</td>
<td>8.4</td>
</tr>
<tr>
<td>Appropriate and targeted information</td>
<td>81</td>
<td>8.6</td>
</tr>
<tr>
<td>Hospital clean/food good</td>
<td>79</td>
<td>8.3</td>
</tr>
<tr>
<td>Info about treatment &amp; side-effects</td>
<td>74</td>
<td>8.8</td>
</tr>
<tr>
<td>Staff sensitive to patient’s feelings</td>
<td>71</td>
<td>7.9</td>
</tr>
<tr>
<td>Need to understand illness</td>
<td>69</td>
<td>8.4</td>
</tr>
<tr>
<td>Info about signs/symptoms of recurrence</td>
<td>67</td>
<td>8.7</td>
</tr>
</tbody>
</table>
Cancer patient needs:

- 24+ needs experienced by >50% patients
- 47+ needs experienced by >25% patients
- Needs reported by >25% rated as salient >7/10 AND unmet/partially met <6/10 include:
  - Worries about recurrence/spreading
  - Genetic information
  - Lifestyle changes
  - Difficulties in intimate relationships (due to cancer/treatment)
  - Worries about death and dying
## Most Frequent Carer Needs

<table>
<thead>
<tr>
<th>Need</th>
<th>%</th>
<th>Saliency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff sensitive to patient’s feelings</td>
<td>89*</td>
<td>8.7</td>
</tr>
<tr>
<td>Clear straight-forward information</td>
<td>87</td>
<td>9.3</td>
</tr>
<tr>
<td>Info about treatment and side-effects</td>
<td>87*</td>
<td>9.3</td>
</tr>
<tr>
<td>Staff sensitive to family’s feelings</td>
<td>83*</td>
<td>8.9</td>
</tr>
<tr>
<td>Quick test results</td>
<td>82*</td>
<td>8.9</td>
</tr>
<tr>
<td>Open and sincere clinicians</td>
<td>82</td>
<td>8.9</td>
</tr>
<tr>
<td>Appropriate targeted information</td>
<td>77</td>
<td>8.9</td>
</tr>
<tr>
<td>Info to understand the illness</td>
<td>78</td>
<td>9.6</td>
</tr>
</tbody>
</table>
Carer’s own needs

- 69% worried about recurrence/spreading
- 59% depressed/sad/low
- 40% financial/benefit advice
- 38% info about local support groups
- 30% help identifying community services
  - 25 needs experienced by >50% carers
  - 47 needs experienced by >25% carers
  - 17 salient needs (>7) unmet/partially met (<6)
Unmet needs…

- associated with greater psychological distress
- predictive of reduced quality of life

*(Hwang et al. 2004; Morasso et al., 1999)*

High levels of unmet need identified across a range of cancer sites e.g:

- bowel *(Galloway & Graydon, 1996)*
- breast *(Girgis et al, 2000)*
- gynaecological *(Beesley et al, 2008)*
- prostate *(Rozmovits & Ziebland, 2004)*
- skin *(Bovevski et al 2000)*
- lung *(Li & Girgis, 2006)*
### Unmet needs and mood

- **Controlling for earlier levels of relevant POMS domain:**
  - Tension/anxiety: Symptom control needs \(0.6095^*\)
  - Vigor: Treatment/care needs \(-0.534^\uparrow\)
  - Anger: Emotional needs \(0.708^{**}\), Experiential needs \(0.741^{**}\)
  - Confusion: Symptom control needs \(0.608^*\)
  - Fatigue: Symptom control needs \(0.532^*\)
  - Depression: Experiential needs \(0.499^\uparrow\), Service needs \(-0.569^*\)
So……

- That’s a small part of a large area of work carried out by academic health psychologists in conjunction with NHS colleagues
- Impact and relevance obvious
- Challenge is getting evidence into-
  - Practice (successes in dr-pat communication? Needs assessment? NHS posts for psychologists?)
  - Policy (success in consultations with DoH on white papers, Healthy Lives, Behaviour Change, NICE guidelines in various conditions)