

## **Illness Representations**

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### **General Description and Theoretical Background**

Illness representations are patients' **beliefs and expectations about an illness** or somatic symptom. Illness representations are central to Leventhal's **Self-Regulation Theory** (Leventhal, 1970; Leventhal, Meyer, & Nerenz, 1980). Self-regulation theory postulates that illness representations determine a person's appraisal of an illness situation and health behavior. The self-regulation framework is conceptualized as a **parallel processing framework**. One processing arm is dedicated to the cognitive processing of an internal or external stimulus and the second, parallel processing arm is dedicated to the processing of the emotional aspects of that stimulus. One implication of this parallel processing is that health behaviors can be triggered as a result of cognitive as well as emotional processes (Leventhal, Diefenbach & Leventhal, 1992).

More concretely, research has identified six attributes or **components of illness representations**:

- Identity, the name or label of a threat (e.g., sore throat, arthritis)
- Timeline, the threat's believed time trajectory (e.g., acute, chronic, cyclical)
- Consequences, the believed consequence of a threat (minor or major)
- Cause, the threat's causal mechanism (e.g., hereditary, external, internal)
- Control/cure (Lau & Hartmann, 1983), whether something can be done to control the threat
- Illness coherence (Weinman & Petrie, 1986), whether a person thinks about the threat in a coherent way.

Two examples help to explain how attributes construct an illness representation. The first example starts with a sore throat. An individual might identify the sore throat as the beginning symptoms of a cold (label). The initial cold label determines that it is an acute condition (timeline), with minor consequences, potentially caused by a number of factors. It can usually be cured (control/cure). Taken together, these attributes of the illness representation making up the "cold profile" will lead the individual to engage in **common-sense health behaviors**, such as drinking lots of fluid, getting some rest, and combating the cold symptoms with over-the-counter remedies. The emotional reactions during these cognitive processes, as conceptualized in the parallel processing model, are likely to be muted, maybe ranging from annoyance about the potential impact on work to worrying that the cold is a precursor to something more serious (illness coherence).

Another example illustrates the use of illness representations in the cancer area. A woman detects an unusual lump in her breast. For a lot of women, the first thought that comes to mind is "cancer" (identity). The cancer label will trigger thoughts about suffering and potentially life-threatening consequences, prolonged treatment (cure) and probably uncertain cause beliefs. Simultaneously, an intense emotional reaction of anxiety and fear is triggered. This is the reason cancer is often times called a "hot cognition," where illness representations and their affective reactions are fused together.

Illness representations are shaped by two types of memories. The first type represents memories that are **conceptual or propositional**, in other words, knowledge that is based on the individual's abstractions of illness experiences. This is in contrast to **schematic** memories, the second type of memory, which represent the memory of prior illness episodes and its emotional associations (i.e., experiences of what the health threat felt like).

### **Related Conceptualization**

Illness representations are one class of illness cognitions which in a general sense might also include other cognitive constructs related to health threats, including perceived vulnerability, optimism and self-efficacy beliefs, as well as perceptions of social norms. Although these cognitions have not been part of the traditional conceptualization of the self-regulation framework, they have been incorporated into expanded versions of the self-regulation framework, such as the **Cognitive-Social Health Information Processing (C-SHIP)** model (Miller, Shoda, Hurley, 1996; Miller & Diefenbach, 1998). Rather than focusing on the role of the six illness attributes, their interactions with affect, and their effect on health behaviors, the C-SHIP takes a more expansive view of the different variables that effect behavior. Specifically, this model postulates the existence of five units through which different cognitive and emotional variables are being processed. The following processing units have been postulated:

- encodings and constructs (e.g., personal risk perceptions)
- beliefs and expectations (e.g., self-efficacy expectations, optimism, illness beliefs)
- goals and values (e.g., the goal of being physically fit and to value ones health)
- affect and emotions (e.g., cancer-relevant anxieties and worries)
- self-regulatory competencies and skills (e.g., coping skills)

The units are linked through a network of connections that variously are activated or inhibited. For example, a person is likely to adhere to a recommendation to get screened for breast cancer, if she feels at risk for breast cancer, is optimistic that the mammogram will be negative, prizes her health, is moderately worried about developing cancer, and has the necessary personal and financial resources and skills to obtain a mammogram. To date, the C-SHIP has found most of its application in behavioral research w

### **Constructs and Measurement**

#### **a) Early assessments and ad hoc measurement of illness representations**

Early measurements of illness representations consisted of a mixture of closed and open ended questions. Open ended questions are often times used by researchers at first to assess the content of an illness belief. Thus, the use of open ended questions informs scale development for closed ended questions and allows the adaptation of the illness representation construct to a new area of illness beliefs.

- **Identity** was assessed with a question, such as “Do you have a name for the condition” (yes/no), and a follow-up, open-ended question “Can you tell me what it is?” “How can

you tell?" (Diefenbach & Leventhal, 1996). In other instances, when the patient does not know the identity of a condition, the occurrence of commonly experienced symptoms (i.e., pain, headaches, breathlessness, and sleep difficulties) has been assessed. Patients answer items on a 5-point rating scale (1 = not at all – 5 = very) or a yes/no dichotomous scale (Weinman, Petrie, Moss-Morris, & Horne, 1996).

- **Timeline** can be assessed with the following question: "Do you think your condition is something that will go away after a couple of days, such as a cold; will come and go, such as an allergy; or you will have forever, such as diabetes?" Patients select the option that best fits their beliefs.
- The **Consequence** attribute can be assessed with the following question: "Do you think your symptom/condition is minor, severe, or life threatening?" Patients are asked to select the option that best fits their beliefs.
- **Causal attributes** have been assessed with threat-specific causes, often derived from patient interviews or focus groups. For example, "Please indicate how much you agree or disagree with the following reasons as causes for your symptom/condition." (Format e.g., 1 = completely disagree; 5 = completely agree).
- The **control/cure attribute** can be assessed with a question such as, "Something can be done to cure the symptom/condition (1 = completely disagree – 5 = completely agree).

#### **b) The Illness Perception Questionnaire (IPQ)**

The popularity of the self-regulation approach among researchers prompted the development of a measure to systematically assess the five illness representation attributes with 38 items (Illness Perception Questionnaire, IPQ; Weinman et al, 1996). **Illness Identity** is assessed with a 12-item core symptom list that is answered on a four-point Likert scale (1 = never; 2 = occasionally; 3 = frequently; 4 = all of the time). Core symptoms focus on general symptomatology, such as pain, nausea, breathlessness, weight loss, fatigue, stiff joints, sore eyes, headaches, upset stomach, sleep difficulties, dizziness, and loss of strength. The remaining four illness representation attributes, cause, timeline, consequences and control/cure are rated on a 5-point Likert scale (1 = strongly disagree; 3 = neither agree or disagree 5 = strongly agree). The cause attribute is assessed with 10 items, representing common causal beliefs. The timeline attribute is assessed with three items. The consequence attribute is assessed with seven statements. Finally, the control/cure attribute is assessed with six statements.

The IPQ had been used with diverse patient populations suffering from conditions, such as heart disease (Cooper et. al., 1999), cancer (Buick, 1997), arthritis (Murphy et. al., 1999), diabetes (Griva et. al., 2000), and chronic fatigue syndrome (Heijmans, 1998). These studies found strong support for the existence of the six illness representation attributes. The IPQ can be tailored for use across many different illnesses by modifying the question stem and by altering the instructions to focus on the specific illness under investigation.

#### **c) The Illness Perception Questionnaire-Revised (IPQ-R)**

The **IPQ-R** was developed to improve the measurement properties of two of the subscales (i.e., cure/control and timeline) and to broaden the scope of the original IPQ (Moss-Morris, Weinman, Petrie, Horne, Cameron, and Buick; 2002). The cure/control subscale now distinguishes between personal control and self-efficacy beliefs (six items) and treatment control and outcome expectations (five items). For example, new items that were added to the personal control scale are “The course of my illness depends on me;” and “Nothing I do will affect my illness.” New items added to the treatment control subscale include “My treatment can control my illness” and “There is nothing which can help my condition.” The second subscale that was improved was the timeline subscale that now includes 10 items, including those that assess cyclical beliefs (e.g., “My symptoms come and go in cycles;” “My illness is very unpredictable.”).

Another aspect of the IPQ-R that was neglected in the original conceptualization is the assessment of **emotional representations**. Leventhal’s self-regulation model specifies that individuals have emotional representations and reactions to the health threat, which might lead to emotion-based coping behavior. Consequently, six items assessing emotional representations have been included, such as “I get depressed when I think about my illness;” “Having this illness makes me feel anxious.” The final addition was a subscale measuring a person’s overall coherent understanding of an illness. This illness-related “meta-cognition” is measured with five items, such as “My illness is a mystery to me;” and “I have a clear picture or understanding of my condition.” In total, the IPQ-R consists of 71 items divided into twelve subscales. Psychometric analyses were performed on several patient samples, totaling a combined population of  $N = 711$  patients.

Moss-Morris, Weinman, Petrie, Horne, Cameron, and Buick (2002) used eight different illness groups for the validation of the IPQ-R, including HIV, multiple sclerosis, asthma and type II diabetes patients. Psychometric analysis revealed that all of the IPQ-R subscales demonstrate good internal reliability. Cronbach alpha’s range from 0.79 to 0.89 for the timeline cyclical dimension and the timeline acute/chronic dimension respectively. (Moss-Morris et al., 2002). Test-Retest reliability was investigated at two time points over a three-week period, . Pearson’s correlations ranged from .46 for personal control beliefs to an average of .85 for different risk factor attributions, demonstrating adequate stability for a short time frame.

To determine discriminant validity and to ensure that the IPQ-R dimensions are not just reflective of affective dispositions, Pearson’s correlations were computed between the subscales of the Positive and Negative Affect Scale (PANAS). Correlations between the two PANAS subscales and the all of the subscales of the IPQ were generally small to moderate in size, with the most significant relationship between emotional representations and negative affect (NA) ( $r = .54$ ). This correlation suggested that approximately 29% of the variance of the emotional reaction to illness was accounted for by trait negative affect.

Predictive stability of the IPQ was evaluated with regard to adjustment to illness among MS patients. Illness representations predicted 15% of the variance of adjustment to disease controlling for illness severity. Among the six illness representations, the identity representation was the strongest predictor.

The large number of items of the IPQ-R and the associated time commitment to complete the measure might be perceived as an impediment to its widespread use. For that reason, Cameron and colleagues have used a shortened version of the IPQ-R (Cameron, Booth, Schlatter, Ziginskis, Harman, & Benson; 2005) consisting of a shortened version of the personal control and emotional representation subscales. The personal control scale uses three of the six items and the emotional representation subscale uses four out of six items. The authors report that analyses with data from the original validation study demonstrated that the two subscales exhibited comparable discriminate and convergent validity with questionnaires of other illness beliefs and negative affectivity.

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