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Patients' Perceptions of Their Illness: The Dynamo of Volition in Health Care

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Abstract

A patient constructs a cognitive representation of his or her illness that guides behavior aimed at managing that illness. Patients' models of their illness share a common structure made up of beliefs about the cause of an illness, the symptoms that are part of the condition, the consequences of the illness for the patient's life, how the illness is controlled or cured, and how long the illness will last. Illness perceptions can be measured using questionnaires and also assessed in patients' drawings, which readily show how an illness is visualized. Illness perceptions change rapidly in response to diagnostic results and have been associated with emotional distress, recovery, and disability, as well as with treatment-related behavior such as adherence. Interventions based around changing inaccurate or unhelpful perceptions of illness are an important emerging area of health psychology.

Keywords

illness perceptions, outcome, assessment, intervention, adherence

Illness perceptions are frameworks or working models that patients construct to make sense of their symptoms and medical conditions. A patient's cognitive representation of his or her illness then guides behavior directed at managing the condition (Leventhal, Nerenz, & Steele, 1984). An illness perception comprises a number of interrelated beliefs about an illness and what it means for the patient's life. The major components include how the illness was caused, how long it will last, what the consequences of the illness are for the patient's life and family, the symptoms that are part of the illness, and how the condition is controlled or cured. Research has demonstrated that patients' perceptions of their illness along these dimensions vary widely, even between patients with similar illnesses or injuries.

Patients build models of their illness based on previous personal or family experiences with their disease or information they may have received from medical staff or the general media. These illness models may be specific to the individual and may differ considerably from those of the clinicians giving treatment. Despite this, there is now a large body of literature showing that patients' illness perceptions are related to a range of important health outcomes, including functioning, health care utilization, adherence, and mortality. The growing interest in patients' perceptions of their illness is reflected in the rapidly increasing number of publications in this area over the past 15 years. While much of the published research has focused on the role of illness perceptions in explaining coping and outcomes in patients with a wide range of health conditions (see Hagger & Orbell, 2003), here we will describe some more recent developments. In particular, we provide an overview of research on new approaches for investigating and modifying illness perceptions in order to improve health outcomes and treatment adherence.

Recent studies of how patients' perceptions develop following medical testing and diagnosis have provided some insights into how illness perceptions change in response to diagnostic information. A study of patients undergoing coronary computer tomographic (CT) angiography for diagnosis of heart disease shows how patients' perceptions change rapidly to incorporate diagnostic information that they either have or do not have heart disease (Devcich, Ellis, Broadbent, Gamble, & Petrie, 2011). The results of this study, illustrated in Figure 1, show that patients generally prepare themselves for an unfavorable diagnosis, indicated by higher levels of concern and perceived consequences in both disease and nondisease groups prior to testing. When the outcome is favorable, with no heart disease apparent from the test, illness concern and perceived consequences drop immediately in the nondisease group. Notice also how members of the nondisease group tend to attribute their good result to their ability to control the disease, indicated by higher ratings of personal control over the disease following the test—in a sense, they claim credit for the favorable outcome. The patients

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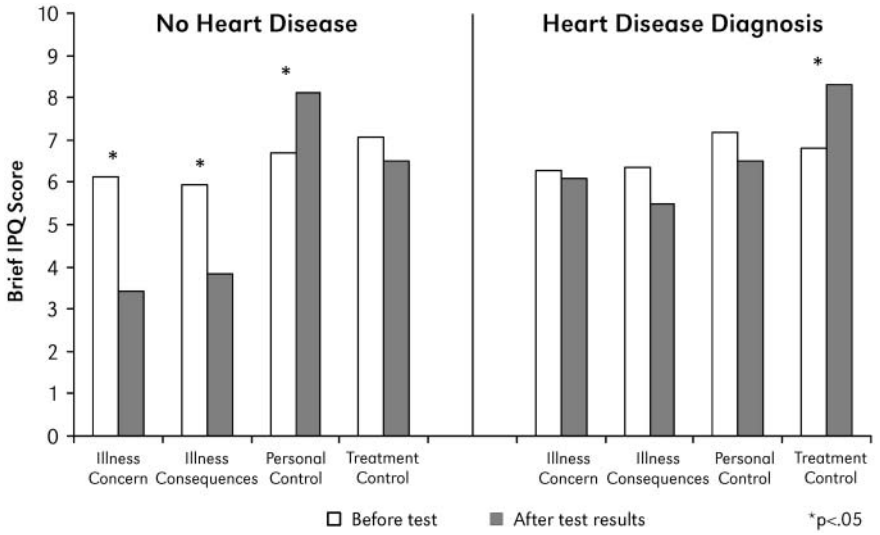

Fig. 1. Illness perceptions (concern about illness, perception of illness consequences, perception of personal control, and belief in ability of treatment to control the disease) before and after CT angiography test results for patients without (left) and with (right) heart disease (differences are based on before–after paired sample *t* tests; adapted from Devcich et al., 2011).

diagnosed with heart disease have a higher belief that their future treatment will control the disease.

Assessing Illness Perceptions

Early work on assessing patients' illness perceptions relied on open-ended questions from structured interviews. More reliable measurement was possible with the development of the Illness Perceptions Questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne, 1996). The IPQ provided assessment of five components of illness representations: identity, timeline, consequences, cause, and control/cure. A later revised version of the scale (IPQ-R) added more items; split the control dimension into personal and treatment control; and added a cyclical timeline, an overall comprehension of illness factor, and an emotional-representation-of-illness scale (Moss-Morris et al., 2002). More recently, a shorter 9-item scale has been developed. The Brief Illness Perception Questionnaire (BIPQ) can be administered quickly and has acceptable psychometric properties (Broadbent, Petrie, Main, & Weinman, 2006). The BIPQ is suited to assessment in clinical situations in which time constraints preclude patients completing the full 80-item IPQ-R.

A recent development in the assessment of illness perceptions has been the use of drawings to uncover how patients think about their illness. The advantage of a drawing is that it provides the opportunity to pick up a patient's idiosyncratic beliefs or misconceptions about the illness that may play a role in determining future outcomes (Broadbent, Petrie, Ellis, Ying, & Gamble, 2004). For instance, a patient who has had a recent heart attack may show in a drawing that his or her heart has been so severely damaged that any activity and strain on the heart may bring on another heart attack. Some characteristics of patients' drawings, such as greater areas of heart damage drawn and larger drawings of the heart over time, have been shown to be associated with important outcomes such as a slower return to work following a heart attack (Broadbent, Ellis, Gamble, & Petrie, 2006) and functional status in patients with heart failure (Reynolds, Broadbent, Ellis, Gamble, & Petrie, 2007).

A drawing also offers the opportunity to see how the patient views the effect of treatment on his or her condition. Figure 2 shows the drawings of two patients before and after undergoing heart surgery. The first patient, whose drawings are shown on the top panels, underwent heart bypass surgery, and the drawings illustrate how the patient's perceptions of his heart as clogged and diseased change over a relatively short period of time. The drawings of the second patient, who had heart valve surgery, also show improved perceptions of the health of his heart, as well as a focus on the rhythm of the heart, which is an important indicator of recovery for this patient.

Illness Perceptions and Outcomes

There is a rapidly growing literature on how patients' illness perceptions relate to later outcomes from illness. The outcomes researchers have examined fall into four major groups: emotional distress, recovery and disability, survival, and treatment-related behavior such as adherence. The central question in this research is this: How does the way a patient views his or her illness or injury affect how the patient deals with the challenges of the illness and eventual outcome? This research is important because it helps inform psychological interventions and can also provide a basis for identifying patients at

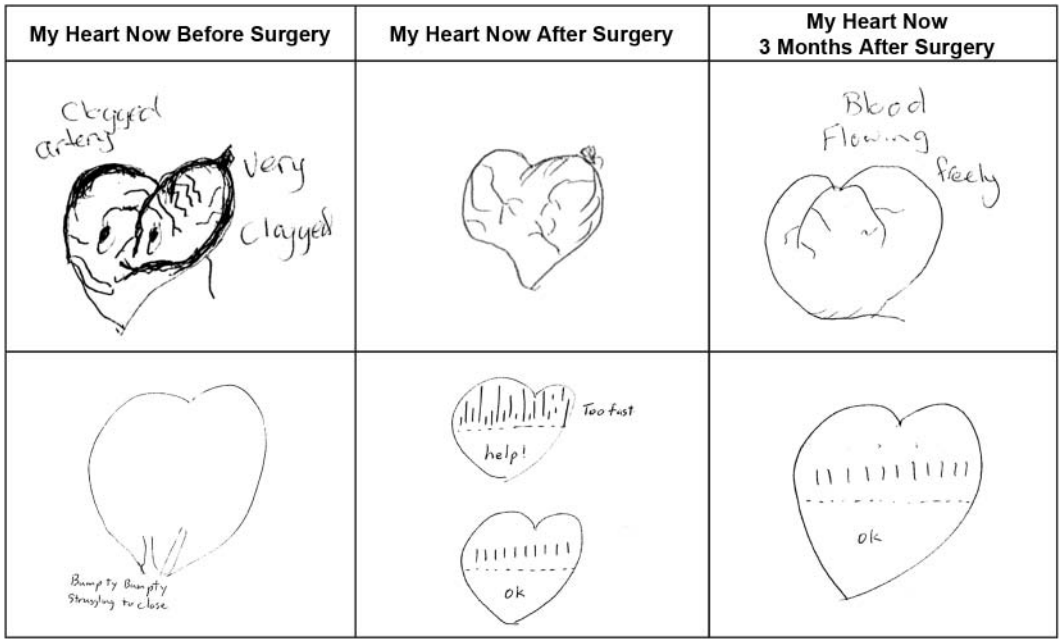

Fig 2. Two heart surgery patients' drawings of their hearts before and immediately after surgery and 3 months later.

an early stage who are at risk of not coping well with their illness.

A number of studies have looked at how illness perceptions predict depression and distress in various illnesses. A meta-analysis of illness perceptions and outcomes found consistent relationships between psychological distress as an outcome and higher perceived consequences, low control/cure beliefs, and longer timeline perceptions (Hagger & Orbell, 2003). In a more recent study, Dickens et al. (2008) measured illness perceptions of 269 first-time heart attack patients and examined their levels of depression over the following year. The researchers found that a patient who developed depression following his heart attack was more likely to believe at baseline that his heart condition would last a long time and was unlikely to be cured.

A number of other studies have now shown that when patients hold negative perceptions about their illness, these beliefs are associated with greater likelihood of future disability and slower recovery (e.g., Galli, Ettlin, Palla, Ehlert, & Gaab, 2010; Kaptein et al., 2010). While it seems possible that negative perceptions are indicative of poorer prognosis, studies have generally found that illness perceptions not only fail to relate closely to objective measures of disease severity but also are often better predictors of outcome. For example, illness perceptions have even been found to predict mortality in a recent study of patients with renal failure. After controlling for both clinical factors and depression, Chilcot, Wellsted, and Farrington (2011) found that perceptions of the ability of treatment to control the disease were a significant predictor of all-cause mortality. One possible explanation of this is that illness perceptions can differentially activate illness-coping procedures such as treatment adherence, which can strongly influence health outcome.

Adherence problems often arise because there is a poor fit between the patient's model of the illness and the nature of the treatment recommendation, which means that the treatment does not really make sense to the patient. For example, heart attack patients who believe that their illness had been caused by their own lifestyle have been found to be more adherent to lifestyle-change advice, whereas those who identified stress or genes as key causes were much less inclined to make these changes (Weinman, Petrie, Sharpe, & Walker, 2000). Timeline beliefs can also influence treatment adherence in a very direct way; Halm, Mora, and Leventhal (2006) have shown that patients who perceive their asthma as only present when they experience symptoms are much less likely to take daily preventer medication than other patients who perceive their asthma as a more permanent condition.

Changing Perceptions to Improve Health Outcomes

Given the consistent findings on the relation between illness perceptions and outcome and the emerging evidence from longitudinal studies, it is not surprising that there is now considerable interest in developing interventions to modify dysfunctional illness beliefs in order to improve patient outcomes. Since direct links have been found between illness perceptions and adherence, illness-perception-based interventions have also been developed in this area.

These interventions aim to modify a patient's perception of his or her condition to increase the goodness-of-fit between the patient's model of illness and his or her treatment. An example of this approach is provided by Karamanidou, Weinman, and Horne (2008), who improved adherence to phosphate-binding medication in patients with end-stage renal disease by providing a concrete illustration of how the medication works, thereby strengthening the patients' understanding of the need to take the medicine regularly. The intervention included a simple demonstration using a plastic container to represent the patient's stomach; phosphate solution was poured in to represent high-phosphate food. Phosphate-binding medication was then introduced, and patients were asked to describe what they saw as they observed the medication binding and solidifying—thus providing a simple concrete image of the mode of action of the medication. Another recent example of this approach to improve treatment adherence is provided by Petrie, Perry, Broadbent, and Weinman (2011), who developed a text-messaging intervention to increase adherence to preventer-medication treatment in young adults with asthma. After an initial assessment of his or her illness and treatment beliefs, each patient was sent targeted text messages aimed at modifying unhelpful beliefs over the next few weeks. This resulted in significant changes in beliefs and in treatment adherence, which persisted for 6 months after the text messages had stopped.

Illness-perception interventions have also been successfully developed for heart attack patients, which have not only successfully changed patients' beliefs about their heart attacks but also improved recovery and return to work (e.g. Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009). The potential for illness-perception-based interventions with patients who have suffered heart attacks is considerable, partly because there is an extensive literature linking illness perceptions and outcome in this patient group and partly because it is possible to intervene at a very early stage prior to hospital discharge. However, successful illness-perception-based interventions have also been developed for other patient groups, including those with type 2 diabetes (Keogh et al., 2011) and psoriasis (Fortune, Richards, Griffiths, & Main, 2004). All of these studies have demonstrated that fairly brief, straightforward psychoeducational interventions can be used for identifying and modifying negative illness beliefs, which in turn can result in improvements in a range of health-related outcomes. Given that adjustment to a chronic illness or recovery from an acute illness often depends upon effective self-management behaviors, it is clear that targeting patients' maladaptive illness perceptions should be integrated into routine care.

Future Research

Examining patients' perceptions of their illness opens up a new approach to examine and intervene in a number of problematic areas of health care. Here we identify what we believe are a few of the many potential applications of examining illness perceptions in the health area and also some of the issues that require attention in order to fulfill the promise of this approach.

One of the most obvious applications of examining illness perceptions is the identification of patients who are at risk of coping poorly with the demands of their illness. There is now a solid evidence base available from meta-analyses (e.g. Hagger & Orbell, 2003) and individual studies with major illnesses enabling us to identify a profile of illness perceptions that puts patients at greater risk of poor outcomes. These profiles differ somewhat by illness but tend to center around negative views of the consequences and control of the illness that may lead to greater emotional distress and a lower engagement with treatment. Identification of at-risk patients offers the potential to intervene with the goal of improving illness adjustment, treatment, and outcome.

Poor adherence to treatment regimens and recommendations is a problem that besets most areas of health care. As previously discussed, the fit between the patient's view of his or her illness and its prescribed treatment is a key area for interventions designed to improve adherence. Often the difficulty here is to develop effective methods that provide patients with a more complete understanding of how and why their treatments match with their illness. This can require either a change in a patient's understanding of the illness or of the recommended treatment or both. The development of successful interventions in this area can have powerful effects on a patient's understanding of his or her treatment and subsequent adherence to the treatment (Karamanidou et al., 2008).

Another important area of application of illness-perception research is in the diagnostic area and improving patients' responses to feedback from medical testing when investigations prove negative. Despite having normal results, many patients remain concerned about their conditions and continue to inappropriately seek medical investigations and treatment for their symptoms. Recent research has demonstrated that changing patients' ideas about the meaning of diagnostic-test results for their health prior to undergoing testing can reduce concern about symptoms, improve reassurance, and reduce future symptom reports (Petrie et al., 2007). As illness perceptions are very sensitive to information given in clinical interviews following diagnostic testing (Devcich et al., 2011), this area has considerable potential for interventions to affect subsequent health care costs.

The modifiability and sensitivity to change of illness perceptions raises important questions about their origin and development over time and, apart from the myocardial infarction studies mentioned previously, few studies have tracked the early progression of illness perceptions in newly diagnosed patients, particularly those with chronic conditions. Such studies would yield valuable information not only about the sorts of factors influencing the formation of patients' models but also about whether there are critical periods during which interventions may be particularly effective. On the more theoretical side, there is also scope for both experimental and

quasi-experimental research to increase our understanding of the ways component illness perceptions link with each other to form an organized cluster of beliefs about the illness and the ways these beliefs relate to emotional processes and to illness-related coping procedures. Recently, Leventhal, Leventhal, and Breland (2011) have attempted to locate the processes involved in illness cognition within a broader cognitive science and neuroscience framework and outline the potential that this approach can offer for further theory development and practical applications. Their analysis points to the huge potential for future interdisciplinary research aimed at uncovering the nature of the many complex processes involved in illness cognition and health outcome.

The ability to identify how patients view their illness offers the potential to examine how medical staff and patients differ in their views of the same illness. Given the large number of potential areas of misunderstanding and miscommunication that exist in health care, it is perhaps surprising that more work has not been undertaken in this area. Surveys that have asked patients to identify the location of body organs like the heart, kidney, and lungs have found that a large proportion of patients cannot correctly identify the location of these major organs (Weinman, Yusuf, Berks, Rayner, & Petrie, 2009). Given the rudimentary medical knowledge that many patients use to construct models of their illness, there is considerable potential to document the areas of major differences between patients and doctors in their views of an illness or injury and the opportunities for each to "talk past each other" when discussing future care. Any health care consultation offers the opportunity to simply ask the patient what he or she thinks is wrong, what he or she believes caused the condition, and what he or she thinks about the proposed treatment.

While health care interventions based around changing patients' illness perceptions have considerable promise, there is much work to do before that promise is realized. More study is needed on the types and timing of psychological interventions that are effective in changing patients' perceptions of their illness and on who is best to deliver such interventions. Given the pressures to lower health care costs, it is important that the interventions that are developed not only improve health care outcomes but also are scalable so they reach across larger populations of patients.

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Declaration of Conflicting Interests

The authors declared that they had no conflicts of interest with respect to their authorship or the publication of this article.

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