ILLNESS PERCEPTIONS: A NEW PARADIGM FOR PSYCHOSOMATICs?

JOHN WEINMAN* and KEITH J. PETRIEΨ

Typically, psychosomatic medicine has seen disease as an endpoint and has focused on the role of psychological factors in etiology or on the psychopathological consequences of illness. In contrast, the illness perception approach begins with the patient's experience of their illness and the main emphasis is on the patient's own model of their condition. Just as people construct representations of the external world to explain and predict events, patients develop similar cognitive models of the bodily changes that reflect either transient symptoms or more long-term illness. We believe that this approach has a widespread application in psychosomatic medicine, because all patients will construct working representations of their illness, and is therefore not limited to those who are regarded as having a pathological response to their condition.

The illness perception approach can be best understood in the context of wider changes in psychology. Since the emergence of contemporary cognitive psychology about 40 years ago [1], the focus on cognition and cognitive approaches has dominated all areas of psychological research and theory. For example, social cognition theories have been extremely influential in social psychology [2] and cognitive behavioral methods are now predominant in clinical psychology [3, 4]. Similarly, social cognition models are central to much research in health psychology as a basis for understanding health related behavior [5]. At the core of the cognitive approach is the view that individuals construct models, internal representations, or schema, which reflect their pooled understanding of previous experiences and are used for interpreting new ones and planning their behavior.

Early work on the perception of physical symptoms identified personal schema, selective attention, and the role of interpretive processes as important in making sense of both normal physiological changes [6] and the symptoms of illnesses such as diabetes [7]. Studies by Leventhal showed that patients' emotional response to changes in tumor size following chemotherapy for lymphoma were a function of their own personal cognitive model of the illness. From this and other studies Leventhal developed a self-regulatory model whereby patients construct their own representations or models which help them make sense of their experience and provide a basis for their own coping responses [8]. This representation contains core components, beliefs about the etiology of the illness, its symptoms and label, the personal consequences of the illness, how long it will last, and the extent to which the illness is amenable to control or cure. These components show logical interrelationships. For example, a strong belief that the illness can be cured or controlled is typically associated with a short perceived illness duration and relatively minor consequences.

Patient models of their illness are, by their nature, private. In medical consultations patients are often reluctant to discuss their beliefs about their illness because they fear conflict with their doctor or risk being thought of as stupid or misinformed. Until recently, the assessment of illness perceptions has been by open-ended interviews designed to encourage patients to elaborate their own ideas about their illness. We have developed a new scale called the Illness Perception Questionnaire that can be used in a variety of physical illnesses and should make assessment more efficient for researchers [9]. Other recent developments have included scales for specific illnesses such as diabetes [10] and a scale to assess specific beliefs about medication [11].

In our work we have found patient models to vary widely across a number of chronic illnesses, even among individuals with the same disease severity [9]. For one person, diabetes may be seen as a relatively minor, time-limited condition caused by a diet high in sugar, whereas another with equivalent disease may see it as a genetic condition lasting for the rest of their life and with catastrophic consequences. From a clinician's perspective it may be very difficult to detect these differences in routine consultations, but they will become apparent in later responses to illness and compliance with treatment. Whereas most current research has focused

*Unit of Psychology, United Medical and Dental Schools of Guy's and St. Thomas's Hospitals, London, UK.
Ψ Department of Psychiatry and Behavioural Science, Faculty of Medicine and Health Science, The University of Auckland, Auckland, New Zealand.

Address correspondence to: Professor John Weinman, Unit of Psychology, UMDS (Guy's Campus), London Bridge, London SE1 9RT, UK. Tel: 44 171 955 4965; Fax: 44 171 955 2727; E-mail: j.weinman@umds.ac.uk.
on coping as a way of explaining illness adjustment and outcome, we believe that illness perceptions may not only explain the variety of coping responses to the same illness but also be more directly related to such outcomes as adherence emotional distress.

Some clear examples of the importance of patient models of illness in directing health-protective behavior, recovery, and disability can be seen in recent work on women with breast cancer in remission, myocardial infarction patients, and chronic fatigue syndrome sufferers. Cameron [13] found, in a clinical placebo-controlled trial of tamoxifen, that the side effects of the active treatment served as a reminder of cancer risk and that by activating these illness representations they triggered associated worries about cancer, resulting in higher levels of breast self-examination. A recent study that we conducted showed that patients' beliefs about their heart attack soon after admission to hospital predicted later attendance at a rehabilitation program and also how quickly patients returned to work and regained normal functioning [14]. The illness perception component most closely related to return to work and functioning was the perceived consequences of the heart attack. Those patients who believed that the illness would have a serious effect on their lives were slower to return to work regardless of the severity of the MI. We have found a similar pattern in chronic fatigue syndrome (CFS) sufferers. Those who catastrophized about the consequences of pushing themselves beyond their present physical state were more likely to report higher levels of fatigue and to be impaired in their ability.

Illness perceptions are central not only for understanding responses to specific diseases but also can be used to interpret patients reactions to genetic testing and health screening data, such as the results of cholesterol tests. Research on the understanding of genetic testing suggests that individuals have quite complex models of the risk of disease and find a simple genetically determined illness hard to conceptualize. More often people see the development of a genetic disease ultimately determined not only by their genetic make-up but also by lifestyle factors such as stress [16]. Much of the current evidence also points to the fact that systematic cognitive biases are employed by individuals to minimize the threatening nature of health information either by downplaying the seriousness of the test result, discrediting the accuracy of the test, or distorting the prevalence of a positive result. Recent work has also shown that memory for health information, such as the results of cholesterol testing was biased in a positive direction with individuals more likely to have reported their cholesterol level as being lower than it actually was, particularly if they had an unacceptably higher cholesterol level [17].

Many interventions currently used in the psychosomatic area such as cardiac rehabilitation and pain management programs, have been developed empirically and are not based on a sound theoretical understanding of underlying psychological processes. In our work to date we have identified a number of specific patient cognitions that can act as either a help or a hindrance to illness adjustment. We believe this approach offers an opportunity for researchers to identify the critical factors in patients' adaptation to illness. Furthermore, this approach can facilitate the development of interventions that modify or take account of specific patient cognitions such as beliefs about the cause or potential for control/cure of an illness. This view of the patient is compatible with the emerging view of health care that sees the patient as taking a more active and informed role. Patients are now requesting a more collaborative relationship in which their beliefs and expectations are acknowledged in consultations and treatment. Early exploration and identification of patients' perceptions offers the opportunity of minimizing or avoiding later difficulties such as nonadherence to treatment or recommended behavior changes. An understanding of illness perceptions is essential for effective patient management, and we believe that this approach has enormous potential for research and practice in the area of psychosomatic research.

REFERENCES


