

The role of illness perceptions in patients with medical conditions

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Purpose of review

In this article we summarize recent investigations into the influence of illness perceptions on outcomes in patients with medical conditions.

Recent findings

Developments in assessment include the publishing of a new brief scale to assess illness perceptions and the examination of the relationship between patient drawings of their illness and outcomes. Recent studies in primary care highlight the importance of patients' beliefs and emotional responses to their illness as being important in influencing their satisfaction with the consultation, reassurance following negative medical testing and future healthcare use. Recent research shows illness perceptions to have associations with a number of outcomes in chronic illness including self-management behaviours and quality of life. As yet, however, few interventions have been developed designed to change illness perceptions and improve illness outcomes. Emerging areas of research include the application of illness perceptions to mental illness and genetic and risk factor testing.

Summary

Research on illness perceptions has confirmed that patients' beliefs are associated with important outcomes in a broadening range of illnesses and risk factor testing. New interventions based on this model have the potential to improve patient outcomes but have yet to be widely developed and applied.

Keywords

chronic illness, illness perceptions, medically unexplained symptoms, reassurance

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Introduction

Illness perceptions are the organized cognitive representations or beliefs that patients have about their illness. These perceptions have been found to be important determinants of behaviour and have been associated with a number of important outcomes, such as treatment adherence and functional recovery [1,2]. There is a consistent pattern to the way patients structure their perceptions of illness. Illness perceptions generally contain an identity component, which includes the name of the illness and the range of symptoms that the patient believes are associated with the condition. They also contain beliefs about the cause of the illness and how long it will last. Furthermore, illness perception components include beliefs about the personal consequences of the condition for the patient and their family, as well as the extent to which the illness is amenable to personal control or to control by treatment [3]. There are two important aspects to note: firstly, patients' beliefs about their condition are often at variance from those who are treating them. In fact, medical staff are usually unaware of patients' ideas about their condition as staff rarely ask patients about their own ideas in clinical consultations. Secondly, patients' perceptions vary widely. Even patients with the same medical condition or injury can hold very disparate views of their illness.

Research investigating the role of illness perceptions in medical conditions has grown rapidly in recent years. This has been spurred initially by the development of scales to reliably measure illness beliefs, such as the Illness Perception Questionnaire, (IPQ), and subsequently by the strong associations found between patients' perceptions of their illness and behavioural outcomes. In this paper we review recent publications examining developments in the assessment of illness perceptions, as well as the role of illness perceptions in primary care patients, patient reassurance and in patients with chronic illness. We end the paper by looking at emerging areas of illness perception research.

The assessment of illness perceptions

Illness perceptions were initially obtained through the use of semi-structured interviews with patients. This method, however, produced quite variable patterns in terms of the quantity and quality of responses and lacked psychometric validity. In response to these drawbacks, the IPQ was developed as a pencil and paper measure for patients [4]. It provided a straightforward assessment of the major components of illness perceptions and could be

tailored to specific illnesses or medical conditions. A later revised version of this scale (the IPQ-R) extended the original scale by adding more items and subscales, including an assessment of patients' perceptions of how well they understand their illness and patients' emotional response to the illness [5].

While the IPQ-R has now been used in well over 100 studies, the scale is long and in many clinical and research situations there is a need for a shorter version, particularly when patients are very ill or when there is limited time available for assessment. Recently, this need has been addressed by the publication of the Brief Illness Perception Questionnaire [6**]. This nine-item scale has good reliability and validity data and most patients can complete the scale in a few minutes. The brief version is most useful for very ill populations and for use in longitudinal research to assess changes in illness representation over time, either as a result of interventions or as part of the illness adaptation process.

Another recent and innovative assessment procedure is the use of patient drawings. So far these have been used in illnesses when patients can easily visualize their pathology. A recent study in myocardial infarction patients found that the size of damage drawn by patients on their heart was associated with a slower return to work and more negative perceptions of their heart condition 3 months later, and was a better predictor of these outcomes than patients' troponin-T levels [7]. Furthermore, by asking patients to draw their hearts again 3 months after their heart attack, a follow-up study found that an increase in the size of the heart patients drew was an indicator of a poorer recovery in terms of increased heart-focused anxiety, complaints of ill health and a higher use of healthcare [8*]. The use of patient drawings is an area that is likely to expand in the future, as valid methods for assessing drawings are developed.

Illness perceptions in primary care

An impressive set of studies conducted by Frosthalm and colleagues [9*] has highlighted the importance of understanding illness perceptions in primary care patients. The studies involved 28 Danish general practices and 1785 patients attending with a new health problem. Patients completed assessments of illness perceptions, physical functioning, and distress prior to seeing the doctor as well as ratings of satisfaction with the consultation following their appointment. The first study found illness perceptions – in particular, uncertainty about their symptoms and emotional distress about the illness – were significant predictors of lower patient satisfaction with the consultation.

A related study demonstrated strong associations between illness perceptions and the later use of health-

care [10**]. Primary care patients who associated more symptoms with their illness, and who had longer timeline and more severe illness consequence beliefs used significantly more healthcare in the 3 years leading up to the study, as well as in the 2-year follow-up period. These three illness perceptions may be critical in predicting future healthcare and the study suggests that discussions with patients about their thoughts and ideas about their illness could help clear up misconceptions and reduce the risk of the health problem developing into a later chronic condition. This study is consistent with a recent investigation of predictors of healthcare use in patients with medically unexplained symptoms attending neurology, cardiology and gastroenterology clinics [11]. The results also showed that the number of symptoms the patient associates with their condition or illness identity was predictive of future healthcare use in the following 6 months. These studies highlight the importance of the patient's beliefs and emotional responses to their symptoms and illness as key factors influencing satisfaction with the consultation and the future use of health care.

Reassurance

A closely related clinical issue is the provision of reassurance in medical consultations and following negative diagnostic tests. Reassurance is a central part of many medical consultations but research shows that the reassurance provided by doctors is often ineffective in reducing patients' concerns about symptoms. Patient's existing ideas about their symptoms and illness may not provide a compatible context to allow them to make sense of the diagnostic result. The continuation of symptoms following a negative diagnostic test can reactivate illness concerns if these are not effectively dealt with at the time of testing and reassurance.

A large number of patients remain unnecessarily worried about symptoms following a negative diagnostic test and a reassuring message and continue to be disabled or use medication and healthcare unnecessarily. While the failure of reassurance has often been blamed on the patient in terms of neuroticism, somatization or hypochondriasis [12,13], the reasons are far more complex. The lack of impact of the reassurance message in medical consultations is due to a number of factors, including the influence of medical testing on health perceptions, as well as both patient and doctor variables. The process of medical testing can, in itself, make feelings of illness vulnerability more salient to patients and reinforce patients' beliefs that there is something wrong with their health. Several studies have found evidence that investigations may not always be useful in reassuring patients, but rather cause harm by creating anxiety and encouraging patients' illness beliefs [14].

A recent study [15^{*}] found that illness perceptions, measured in patients prior to undergoing investigations for chest pain, were important determinants of reassurance immediately following the investigation and 1 month later. Those patients who had already developed ideas that their illness was going to last a long time were the least reassured following exercise stress testing. Another factor that is likely to be important is the delay before the diagnostic test is undertaken. A long delay allows more time for negative illness beliefs to become established [16]. This may include negative or catastrophic ideas about symptoms, as well as a reduction in work hours or leisure activities. All of these factors make subsequent reassurance considerably more difficult.

Coping with chronic illness

The diagnosis of any chronic illness confronts individuals with a collection of tasks necessary for both physical and psychological adjustment. Adjustment may involve acceptance of a certain amount of loss of function. It may also require the acquisition of new skills and changes to daily routines in order for the patient to manage the symptoms of the illness or cope with the demands of treatment [17]. As such, chronic illness places a considerable burden on the individual and can have a significant impact on their quality of life. From earlier research it is clear that the illness perceptions of individuals are highly influential in determining outcomes and adjustment in a number of medical conditions [1,2]. Much of the recent work in the field has focused on extending these findings to other conditions and patient populations.

There has been considerable focus on cardiac patients in the illness perception literature. Of particular interest are the areas of prevention and rehabilitation, although not all studies have found that illness perceptions are predictive of patient outcomes. In a group of myocardial infarction patients, illness beliefs, particularly consequence beliefs, did predict subsequent quality of life [18]. A related finding is that illness perceptions were not strongly related to secondary preventive behaviour in a group of patients with coronary heart disease who were experiencing few cardiac symptoms [19]. Similarly, illness perceptions had only small associations with adherence to cholesterol-lowering medication in patients with familial hypercholesterolaemia [20].

In contrast, some components of illness representations have been found to be significant predictors of diet and exercise self-efficacy in patients admitted to hospital with coronary heart disease [21]. Moreover, a recent meta-analysis [22] concluded that illness perceptions do contribute to the prediction of patients with myocardial infarction attending cardiac rehabilitation. This was particularly so for patients' beliefs about whether their illness could be controlled or cured.

Another emerging area of research is the influence of treatment modality and individual differences such as gender and ethnicity on illness perceptions. A recently published study [23] analysed the illness perceptions of patients with coronary artery disease undergoing surgery, angioplasty, or taking medication to treat their illness. The study found that the medication group perceived their condition as significantly more long lasting than patients in the revascularization groups. Patients saw the revascularization treatments as providing a cure for the condition, whilst the decision to begin ongoing medication may have been seen to be reflective of a more enduring condition. Another study [24] found a number of sex differences in the illness perceptions of cardiac patients. Namely, women perceived a more chronic course for their heart condition than men, while men held greater personal and treatment control beliefs than women.

The association of illness perceptions with outcomes has been found in a number of other illnesses. Kaptein and colleagues [25^{*}] found that illness perceptions of patients with Huntington's disease significantly influenced both psychosocial and physical well being. In patients with type 2 diabetes, perceptions of shorter duration and greater treatment effectiveness were associated with greater diabetes self-management [26]. Furthermore, illness representations correlate significantly with quality of life, both in individuals with chronic kidney disease undergoing haemodialysis [27] and those recently diagnosed with head and neck cancer [28]. In rheumatoid arthritis patients, illness perceptions, particularly consequences beliefs, impacted on a number of domains of well being, including depression, life satisfaction and physical symptoms [29]. Another study focusing on women with rheumatoid arthritis, reported that illness perceptions were associated with concurrent adjustment, depression, pain and physical functioning [30].

Emerging areas of research

There are a number of potentially exciting areas of emerging research with illness perceptions. Research has developed around understanding how patients' specific beliefs about medicines and treatment influence adherence and treatment decisions [31]. Recent research has shown patients' concerns about prescribed medication and beliefs about the necessity of the treatment are related to decisions to start antiretroviral treatment in patients with HIV infection [32] and also to adherence in a number of conditions [33,34^{*},35]. Illness perceptions are also increasingly being applied to the area of genetic testing to examine lay understandings of the meaning of genetic tests [36] and their impact on risk perceptions [37^{**}] and health behaviour [38^{*}].

Research is also developing in the area of mental illness and some important findings are beginning to emerge. In

this field, the focus has primarily been given to schizophrenia. As in physical illnesses, cognitive representations of mental illness are associated with anxiety and depression in schizophrenia patients [39,40] and in individuals with nonaffective psychotic disorder [41]. In relatives of patients with schizophrenia, illness perceptions are related to emotional and behavioural responses to the individual with the illness and distress in the relatives who care for these patients [42].

To date, most illness perception studies have been designed to demonstrate the associations of illness perceptions with behavioural and emotional outcomes of illness. There is now a need in the area for the development of effective interventions designed to change relevant dysfunctional illness perceptions and thus improve outcomes of illness. So far, studies in this area are limited, but one study designed to change illness perceptions in patients following myocardial infarction was successful in reducing disability and speeding return to work [43]. The challenge now exists for researchers to translate research findings showing that illness perceptions are associated with a range of important outcomes into interventions useful for patients.

Conclusions

Over recent years illness perception research has continued to gather momentum. Illness perceptions have been shown to have important associations with outcomes in a range of acute and chronic illnesses. New emerging areas of research attention are in patients' perceptions of treatments and genetic testing. Work is also developing in the area of mental illness. There is now a need for the development of effective interventions designed to help patients change dysfunctional illness perceptions and thus improve the outcomes of illness.

References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (pp. 194–195).

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