Illness perceptions: impact on self-management and control in asthma

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Current Opinion in Allergy and Clinical Immunology 2010, 10:194–199

Purpose of review

Outcome in asthma is determined not only by pulmonary function or other biomedical characteristics. An important determinant of asthma outcome is illness perceptions: patients' subjective beliefs and emotional responses to their illness. Illness perceptions influence patients' coping and self-management behavior, and thereby outcome.

Recent findings

We review recent studies on associations between illness perceptions and outcome in patients with asthma, with a range of respondents and caregivers, with varying degree of asthma severity, and in different settings of medical care. Most studies pertain to substantial numbers of patients, and have been performed in different countries, adding to the external validity of the findings. All studies report substantial effects of illness perceptions on various categories of outcome: illness perceptions reflecting personal control over the illness are associated with a positive outcome, that is, asthma control. Findings point at the importance and clinical relevance of addressing patients' illness perceptions, and suggest that this may improve outcome in asthma care. Well conducted intervention studies on this topic are called for in order to improve outcomes and quality of life in asthma patients.

Summary

Illness perceptions influence the way in which patients with asthma cope and their self-management of the illness. Illness perceptions can be assessed quite easily and directly, they inform healthcare providers about the psychosocial responses of patients towards their asthma, they are responsive to change in the clinical encounter or via self-management intervention training. Exploring patient's illness perceptions, therefore, is a crucial component of good clinical care.

Keywords

asthma, behavioral interventions, illness perceptions, outcome, self-management

Curr Opin Allergy Clin Immunol 10:194–199

1528-4050

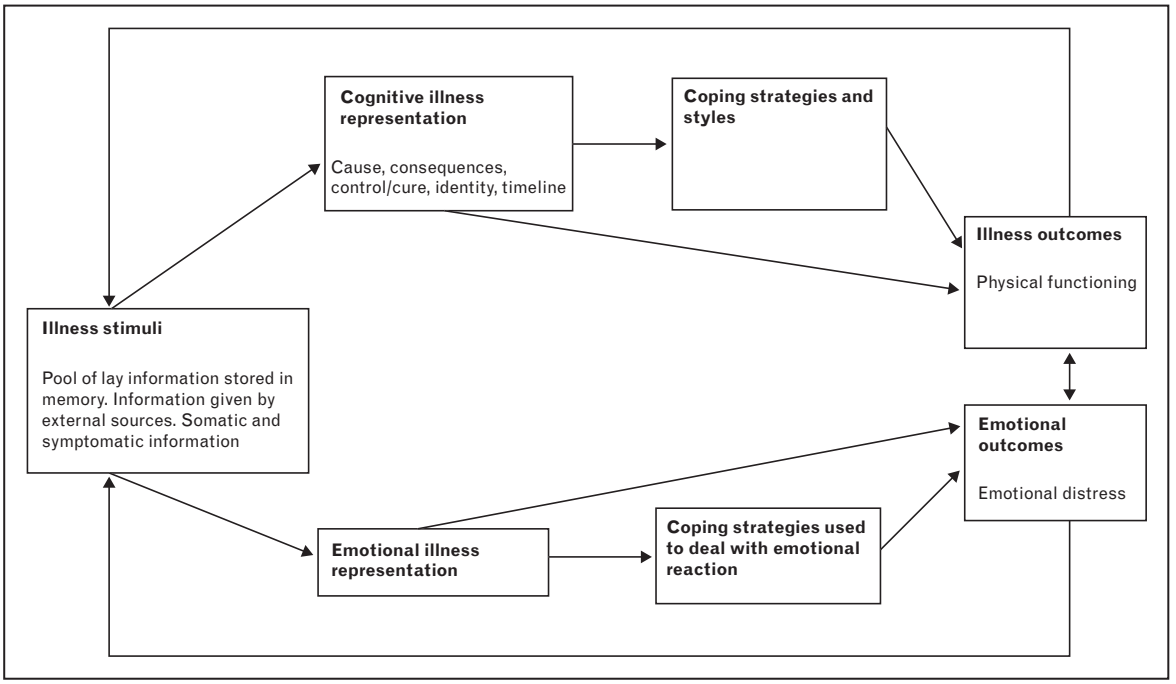
Introduction

Asthma is one of the most common chronic illnesses, affecting millions of adults and children worldwide [1,2]. Over the past decade, the emphasis in asthma management has shifted from treatment decided by level of asthma severity to therapy aimed at achieving full control of asthma [3]. Full control of asthma comprises a combination of little or no asthma symptoms (day or night), little or no use of reliever medication, no restriction of activities, no exacerbations, and normal lung function [4]. Recent evidence-based guidelines highlight the importance of building a doctor–patient partnership to help achieve such asthma control [3]. Despite advances in the evidence base and the availability of asthma guidelines, and the effectiveness of controller medication in randomized trials, however, asthma continues to cause significant morbidity, both in children and in adults [5,6]. The reasons for this paradox are largely unclear and likely to be multifactorial and complex. One factor most likely pertains to the biomedical nature of the guidelines and associated lack of attention for patient views and behavior. In this review, we will illustrate how one component of patient views and behavior, that is, illness perceptions, play an important role in explaining self management behavior and, therefore, outcome.

Importance of self management

Patients with a chronic illness, such as asthma, spend on average 2 h per year in direct contact with a healthcare provider [7]. In the other 8758 h of the year, the patient manages the illness him/herself. Adequate self-management is instrumental in achieving and maintaining satisfactory asthma control [8]. However, the patient is the one who controls the actual use of medication. The

Figure 1 The Common Sense Model (CSM)



Data from [11].

patient, therefore, controls self-management, adherence, asthma control, and quality of life.

Determinants of self management and illness perceptions

Sociodemographic characteristics, such as age, health status, and social class, do not determine self-management, not in asthma, nor in any chronic illness for that matter [9]. Recent research lends support to a theoretical model that explains differences between patients in outcome of the self-management of chronic illness. This Common Sense Model (CSM) states that people try and make sense of a threat to their health in order to try and control the threat [10]. The model is depicted in Fig. 1.

A patient with asthma who perceives her asthma to have an episodic nature will not perceive the necessity to take preventive medication. This 'no symptoms, no asthma' behavior will lead to inadequate control of asthma [12]. On the other hand, a patient who perceives her asthma to be a chronic condition that necessitates maintenance medication will adhere to medication use, therefore, and will have a higher chance of controlling her asthma. A physician who, therefore, quite rightly attempts to change the 'no symptoms, no asthma' illness perception into a more chronic representation of asthma is very wise. However, simply saying to the patient to adopt the chronic illness model will not work. She needs to explore, elicit, and change the illness perceptions of the patient. We will explain later in this paper how this physician may succeed in achieving this.

Patients create their own personal cognitive representation of their illness which includes beliefs about what may have caused the illness, the consequences the illness will have on their lives, how long the illness will last, and whether or not it is controllable or curable. In parallel, they also develop emotional responses to the threat. The cognitive and emotional representations of symptoms and illnesses are called illness perceptions. Illness perceptions shape coping behavior and this in turn determines self-management behavior. If the threat is controlled, the self-management is effective and leads to a good quality of life. If the self-management behavior is perceived to be ineffective by the patient, s/he will try and adjust the emotional and cognitive representations of the threat (or illness) in order to try and achieve control (Fig. 1) [10].

Illness perceptions are shaped by early experiences with illness-related episodes (e.g. flu, fall) where children learn how to respond to pain and discomfort from their parents and by imitating siblings and other children, for example, stay home or continue daily activities as much as possible [10]. In addition, public images of how to respond to various complaints and illnesses are learned by watching television, surfing the Internet, lay press

publications, listening to stories of parents, teachers and physicians. Illness perceptions therefore, have cultural, social and psychological determinants, and are not determined by 'objective' medical severity of the symptoms or sociodemographic characteristics of the patients.

Assessment and components of illness perceptions

Illness perceptions may be assessed by questionnaires, interviews, drawings, and analyses of stories, novels or poems [13,14]. They are usually separated into cognitive and emotional representations of illness. Cognitive representations pertain to cause, consequences, control/cure, identity, and timeline. Emotional representations encompass anxiety and depression ('psychological distress'). As in various parameters of pulmonary function, a number of dimensions of illness perceptions are distinguished.

Identity assesses the number and nature of complaints that a patient attributes to an illness or complaint (e.g. shortness of breath). Cause reflects the perception of factors that cause the particular illness (e.g. allergy, but also 'stress'). Consequences are the effects of the illness on daily life: functional, social, and psychological (e.g. absence from school, limitations in sexual activity). Control/cure relates to how a patient perceives him/herself to be able (or unable) to control the illness (e.g. via medication or relaxation). Timeline reflects whether patients perceive their asthma to be an episodic affliction or a chronic illness (with major consequences for the nature of self-management). In the box with 'cognitive illness representation' in Fig. 1, more recent cognitions have not yet been incorporated. Research suggests that coherence (i.e. the degree to which a person is able to make sense of his/her illness) is another important aspect of 'making sense of an illness'. In addition, the cure/control dimension can be separated into personal control and treatment control. Emotional representation is usually assessed by assessing psychological distress [15].

In the model (Fig. 1), coping is assumed to be a factor linking illness perceptions and outcome. The figure, however, also shows a direct link between illness perceptions and outcome. These two views illustrate the state-of-the-art of illness perceptions research: the place and importance of coping in the CSM have changed based on recent studies in which coping did not appear to contribute greatly to explaining differences between patients in disease outcomes [11,16].

The historical background and introduction of the CSM in asthma have been described earlier [17•]. In the current paper, we specifically focus on studies that applied the concepts of the Common Sense Model to various samples of patients with asthma, of various age groups, in various medical settings, and in various geographic locations.

Methods

A literature search in PubMed with 'asthma and illness perceptions' was performed. Publications after 2000 were selected. The retrieved publications were reviewed for relevance. In the context of our paper, we aimed at presenting a narrative review of major publications. A systematic review is beyond the scope of this paper, given the overall objective to illustrate the topic of illness perceptions in asthma.

Results

Illness perceptions are a MESH-term in PubMed, confirming the importance and relevance of the concept in medical care and research. Combining illness perceptions with asthma yielded 225 publications (21 December 2009). After screening, 19 recent papers were selected. The retrieved papers, reflecting a wide age range, degree of severity, and setting, are summarized in Table 1 [18–35].

Two review papers deserve separate mention. Drotar and Bonner reviewed determinants of adherence to pediatric asthma treatment, and found that parental beliefs about the illness and its treatment relate to adherence–a finding that is consistent with the studies summarized in Table 1 [36•]. Janssens *et al.* [37•] discuss a cognitive–affective framework of symptom perception in asthma, and report how cognitions and emotions impact on perceptual accuracy, asthma control and quality of life in asthma patients. Both review papers are important in the context of the current paper, and support the review of empirical studies summarized in Table 1.

Discussion

The results in Table 1 represent current knowledge on the topic of illness perceptions and asthma. The review shows that studies on this topic have been performed in various countries across the world, with relatively large numbers of patients, strengthening the external validity of the findings. Also, most studies have been performed in adult patients with asthma. Additional research in children and adolescents with asthma, therefore, seems warranted. The same goes for studying healthcare providers and their illness perceptions, and the effects of these on clinical decision making. In most studies described in Table 1, illness perceptions were assessed by questionnaire, allowing comparisons between studies. Asthma specific questionnaires assessing illness perceptions, adequately translated into additional languages

Table 1 Summary of studies on associations between illness perceptions and asthma outcomes (2000–2009)

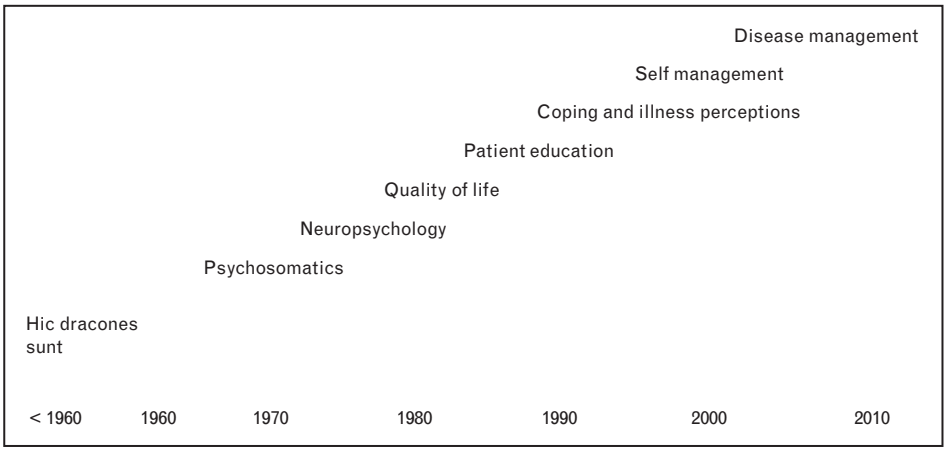
First author Year Country	# Patients age category setting	Assessment of illness perceptions	Results
[18] Adams 2004 Australia	834 Adults general population	Emotional representations; SF-12*	Higher anxiety, depression and stress, and lower perceived control in patients with asthma, compared with nonasthmatics; absence from work and limitations in daily activities associated with higher emotional representations and poorer SF-12 scores
[19] Bergström 2008 Sweden	37 Adolescents outside and in hospital	Questionnaire; interviews with next-of-kin and healthcare professionals; medical record	Psychosocial problems are risk factor for death due to asthma
[20] Bokhour 2008 USA	37 Parents of children aged 5–12 years with asthma outpatients	Interviews explored parents' explanatory models about asthma management	Nonconcordance is explained by parental explanatory models
[21] Calfee 2006 USA	865 Adults in-patients	Perceived control	Lower perceived control is causally related to hospitalization and emergency department use
[22] Chen 2003 USA	115 Adult caretakers in-patients	Beliefs ('prevent worse', 'stop asthma', 'asthma act up')	Rehospitalization is associated with caretaker's beliefs about controlling asthma
[23] Clark 2007 USA	808 (Females) adults outpatients	Self-monitoring of asthma beliefs and problem-solving skills	Improvement of symptoms, healthcare use, days missed work or school, following intervening in self-monitoring and problem-solving skills
[24] Halimi 2007 France	73 Adults outpatients	Control beliefs	Control predicts hospitalization
[11] Halm 2006 USA	198 Adults ex-hospitalized	'No symptoms, no asthma': illness beliefs and self-management behaviors	'No symptoms, no asthma' belief associated with low adherence and poor self management
[25] Jessop 2003 UK	330 Adults primary care	IPQ-R*	Cognitive and emotional representations of asthma predict adherence
[26] Jones 2008 UK	50 Adults outpatients	Qualitative interview re life events perception, psychosocial factors, coping	Psychosocial problems and life events are associated with delay in seeking medical help and with hospital admission
[27] Koinis 2008 USA	100 Adults primary caregivers from Latino descent	Interviews re beliefs about asthma causes, symptoms, and treatment	Cultural beliefs about asthma and asthma practices are associated with asthma treatment
[28] Laforest 2009 France	204 Adults primary care	Questionnaire about beliefs and behaviors re medication	'No symptom, no asthma' patterns
[29] Main 2003 New Zealand	42 Adults outpatient	IPQ-R*; negative mood	Negative mood and symptom labeling increase reliever use, irrespective of lung function
[30] Mancuso 2008 USA	257 Adults outpatients	Emotional representations; according to patient and physician	Patient-reported emotional representations, not physician-reported emotional representation, associated with asthma control
[31] Menckeberg 2008 Netherlands	238 Adults outpatients	Beliefs about medicines	Beliefs about medicines correlate with inhaled corticosteroid adherence
[32] Mora 2007 USA	177 Adult inpatients	Negative affectivity; asthma worry; worry about medications; symptom attribution	Worry increases vigilance to symptoms
[33] de Peuter 2008 Belgium	72 Adults outpatients	Asthma symptom checklist; negative affectivity; catastrophizing	Catastrophic thinking drives symptom overperception
[34] Wirrell 2006 Canada	38 Asthma, 41 healthy adolescents open population	Perceptions about physical and social impact; reluctance to befriend	Asthma perceived less negatively than other chronic physical illnesses
[35] Yoos 2007 USA	228 Children outpatients	Parental beliefs about asthma; parent – healthcare professional relationship	'No symptom, no asthma' model in parents determines medication use

*IPQ-R, Illness Perception Questionnaire – Revised; SF-12, Short Form 12 items: a measure for functional status ('quality of life').

other than English, would be beneficial in future research efforts.

Generally speaking, the associations between illness perceptions and outcome are in line with findings in other diseases [15]. Applied to asthma, the major results of the studies in Table 1 illustrate how cognitions that reflect a high degree of personal control, treatment control, a strong representation of asthma as a chronic illness necessitating maintenance medication, concordance between healthcare provider and patient (or his/her care taker) regarding maintenance therapy and self management, and low level

Figure 2 Behavioral research in asthma 1960, current



The psychological approaches to patients with chronic illness in the past half century (x axis), showing how patients increasingly have become more empowered in taking matters into their own hands (y axis). Data from [40].

of emotional representations (also low-negative affectivity, low-level of catastrophizing) are associated with minimal disturbances in functional outcome and quality of life. On the other hand, illness cognitions that reflect high perceived consequences, low-personal control, low-treatment control and low coherence are associated with major limitations in functional status and quality of life.

Clearly, the findings reviewed here have important clinical implications. If illness perceptions impact on outcome, then changing illness perceptions should result in changes in outcome. This 'paradigm' indeed has been shown to be valid. In a study in patients with myocardial infarction, eliciting, addressing and changing patients' illness cognitions led to improvement in symptoms and social and work limitations [38]. In asthma, similar studies are still waiting to be performed, although a recent Cochrane review suggests that this approach should be beneficial in asthma as well [39].

Figure 2 depicts the psychological approaches to patients with chronic illness in the past half-century (x axis), showing how patients increasingly have become more empowered in taking matters into their own hands (y axis). The current emphasis on disease management combines patient involvement, patients' views and a healthcare provider who is willing and able to involve the patient in managing his/her chronic illness as much as possible in the 8750 h per year when the patient is not in a medical setting.

Clinical implications

In patients where 'optimal' medical management does not lead to maximum asthma control, the clinician may explore the illness perceptions of the patient (and his or her caretaker, in younger patients). Listening to the perceptions of the patient about asthma, having the patient fill out the B-IPQ (Brief Illness Perception Questionnaire; [41]), or asking the patient to make a drawing of asthma may demonstrate an inadequate set of illness perceptions about the asthma, where patients adopt a 'no symptoms, no asthma' strategy. These patients ignore symptoms, do not use the prescribed medication adequately and therefore, run into major derailments of asthma (i.e. exacerbations, hospitalizations, death). If inadequate illness perceptions have been found, a nurse or a psychologist may discuss and attempt to change the patient's illness perceptions, together with a physician and, of course, active involvement of the patient (see Fig. 2) [40].

Conclusion

Patients with asthma have no option but to self-manage their illness, with evidence-based optimal medical care to help them fulfill this complex task. Self-management is determined by behavioral factors mainly – and not that strongly by sociodemographic (e.g. age, socioeconomic status) or clinical (e.g. pulmonary function, hyperreactivity) characteristics. One such behavioral factor is illness perceptions, the subjective cognitive and emotional representation of asthma symptoms and asthma management. On the basis of our review of empirical studies about illness perceptions in patients with asthma, it can be concluded that these representations predict various aspects of asthma outcome and asthma control. Given the empirical evidence on the effect of changing illness perceptions in patients with other chronic somatic disorders, studies in patients with asthma where illness perceptions are addressed and changed are called for

in order to help the patient, his/her social environment, and the healthcare professional achieve optimal asthma control and quality of life.

References and recommended reading

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

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- •• of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (p. 268).

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