Illness Perceptions About Asthma Are Determinants of Outcome

AD A. KAPTEIN,1,* BRIAN M. HUGHES,2 MARGREET SCHARLOO,1 MAARTEN J. FISCHER,1 JOHN WEINMAN,3 AND KLAUS F. RABE4

1Unit of Psychology, Leiden University Medical Centre (LUMC), Leiden, The Netherlands
2School of Psychology, National University of Ireland Galway, Galway, Ireland
3Unit of Psychology, King’s College London, London, UK
4Department of Respiratory Medicine, Leiden University Medical Centre (LUMC), Leiden, The Netherlands

This article reviews an emerging area of research on patients with asthma: namely, illness perceptions and their relationships with various aspects of outcome. The article briefly introduces the Common Sense Model, outlining the relevance of how “lay” patients conceptualize symptoms, illness, and treatment. On the basis of a comprehensive literature search, nine empirical studies illustrating the relationships between illness perceptions and outcomes are discussed. It is concluded that further research should focus on assessing asthma-specific illness and treatment beliefs. Also, given the effects of intervention studies in illness perceptions in other patient categories, it is recommended that serious consideration be given to intervention studies focusing on eliciting and changing illness perceptions in asthma patients, especially in those whose self-management seems to be inadequate.

Keywords asthma, illness perceptions, Common Sense Model, review, quality of life, self-management

INTRODUCTION

Outcomes of medical management in patients with chronic illness are determined not only by objective factors but also by behavioral and social factors (1). For example, research in children with asthma has made clear how parent-reported family burden can predict quality of life (2). Similar findings are reported in adults. Low-control beliefs about life events have been found to be associated with difficult-to-control asthma in adult outpatients (3), while in research on hospitalized adults with asthma, depressive symptoms have been associated with poor adherence and increased risk of adverse asthma-related outcomes (4). The implications of such findings are increasingly incorporated into guidelines for asthma management and translated into written action plans and self-management instructions (5). This area has developed to such a degree that the number and quality of the available empirical studies is now sufficient to allow the writing of a number of Cochrane reviews (6).

In both research and clinical contexts, consideration of psychosocial aspects of asthma (and of respiratory disease in general) has a long tradition. Indeed, in the very early days of behavioral medicine, asthma was considered by psychoanalytic theorists to be one of the few entirely psychosomatic illnesses (7). However, in subsequent years, such anec-dottally driven theories have been found to be empirically unsupportable. Instead, contemporary research has seen the development of three distinct empirically based behavioral approaches to asthma (8).

Learning theory approaches consider asthma symptoms to be responses that are under the influence of reinforcement (rewards) or negative consequences (punishment). Relaxation therapy, biofeedback, and systematic desensitization are three resultant techniques to be applied in empirical studies on asthma patients. However, the effects of these techniques on outcome measures, such as pulmonary function and use of health care services, have been rather unimpressive (9).

The second empirically based behavioral approach to asthma focuses on self-management. In a narrow sense, self-management pertains to providing patients with written action plans that instruct them on when and how to use and adjust asthma medication, usually in combination with the monitoring of pulmonary function by patients (6). In general, behavioral scientists adopt a broad perspective in that they maintain that self-management also encompasses the psychological and social management of living with a chronic illness (10). In contrast to learning theory (or psychoanalytic) approaches, self-management interventions tend to be associated with meaningful improvements in outcomes. In a review of self-management in asthma, Newman et al. report positive effects on clinical and laboratory assessments, symptoms, functioning, quality of life, and use of health care services (11).

The most recent approach in psychosocial research and care pertains to self-regulation and is sometimes referred to as the “Common Sense Model” (12). In this approach, patients with asthma—or, for that matter, with any illness—are seen as constructing a lay theory that comprises their perceptions of the causes, course, consequences, timeline,
and identity of their illness. These views are formed as a consequence of what physicians tell patients but also of what patients learn from informal sources such as popular publications, television programs, and fellow patients. Such illness perceptions have been found to determine coping behavior, self-management behavior, adherence, and outcomes (such as use of health care services, days off work, school absenteeism, and quality of life [13]).

Illness perceptions in asthma are easily categorized into the five dimensions distinguished by the Common Sense Model. Illness perceptions in the identity dimension comprise the complaints, signs, and symptoms that patients attribute to their asthma. Examples of illness perceptions that belong to the causes dimension include perceptions that asthma is caused by “stress,” “heredity,” or “the weather.” A cure/control illness perception could be the view that “There is nothing that can help my condition.” For the consequences dimension, an illness perception such as “My asthma is not a serious condition” would be an example. Timeline perceptions are particularly relevant for asthma patients in that patients who agree with statements such as “My illness will last a short time” or “My illness will improve in time” have been found to manifest poor outcomes. For example, in a recent paper entitled No symptoms, no asthma, scrutiny of timeline-related illness perceptions among 198 adults with asthma allowed the authors to conclude that: “The single question of, ‘Do you think you have asthma all of the time, or only when you are having symptoms?’ can efficiently identify patients who are not predisposed to think about or manage their asthma as a chronic disease” (p. 579, 14). In other words, it was found that illness perceptions relating to timeline could be used to identify those patients who have a high risk of non-adherence to standard treatment guidelines.

The first studies to successfully use interventions based on illness perceptions in clinical samples have now been published. As an example, Petrie et al. (15) found that an illness perception-based intervention produced a number of enhanced outcomes (including earlier return to work and reduction in symptoms at follow-up) among a sample of myocardial infarction patients when compared to controls. The aim of the present review is to consider the topic of illness perceptions in relation to asthma and to discuss a suitable research agenda to help physicians and patients achieve adequate outcomes in asthma care. Throughout, recommendations for future research on illness perception interventions that might produce positive outcomes for asthma patients will be offered.

**METHOD**

We systematically searched the literature in PubMed, PsycINFO, and EMBASE for empirical studies on asthma and illness perceptions in patients of all ages (see the Appendix for the precise search strategy used). In our current narrative review, we selected studies from these searches that illustrate research based on: (a) various age categories of patient (young children, adolescents and their parents, adults); and (b) various methods of assessing illness perceptions (questionnaires, interviews, drawings). This resulted in nine studies that illustrate the topic of illness perceptions in asthma, which are reviewed here.

**RESULTS**

The characteristics of the nine selected studies are summarized in Table 1 (14, 16–23).

The study results shown in the final column of Table 1 represent empirical support for the Common Sense Model (which, in the literature, is occasionally referred to as the Self-Regulation Theory). Several of the studies present data on the associations between illness perceptions on the one hand and adherence to asthma medication on the other. In the study by Byer & Myers (16), adherence to asthma medication was assessed by patient self-report, number of preventer inhaler prescription, and number of reliever inhaler prescriptions. Multiple regression analyses showed that various dimensions of the Illness Perception Questionnaire (IPQ) predicted adherence. Illness perceptions relating to the dimension’s causes, timeline (e.g., “asthma has a long illness duration”), and identity (e.g., “many complaints are due to asthma”) were associated with adherence. The studies by Cohen et al. (18), Halm et al. (14), Horne et al. (19) and Jessop et al. (20) also examined the contribution of illness perceptions to medication adherence. In all studies, illness perceptions were strongly associated with adherence: Patients who reported low perceptions of control, who held an episodic belief about asthma (timeline), and who perceived their asthma as having few adverse consequences were less adherent.

In a group of adolescent asthmatics, Cohen et al. (18) investigated the contribution of illness perceptions to two types of self-management behavior, namely the taking of an inhaler to school and the use of preventer medication. Control perceptions over asthma symptoms were associated with better self-management. In this study, an emotional representation of asthma (namely, embarrassment) was also examined. It was found that those asthmatic adolescents who were embarrassed about their asthma were significantly less likely to take their asthma medication with them to school. This study fits within a more recent conceptualization of the Common Sense Model that is extended to include an elaborate emotional representation dimension (12). This extension is reflected in the design of the Illness Perception Questionnaire–Revised (IPQ-R)(24), which contains items aimed at different types of emotional representation (anxiety, depression; e.g., “I get depressed when I think about my illness,” “My illness makes me feel afraid.”) as well as items aimed at a proposed dimension of coherence (e.g., “My illness is a mystery to me.” “My illness doesn’t make any sense to me.”)

Another application of illness perceptions research is represented by investigations of the degree to which illness models of parents are discordant with those of professionals (e.g., health care providers) and the consequent impact of such discordance on asthma management in adolescents. In the study by Yoos et al. it was found that parental and professional models of asthma tended to differ markedly. However, it was also found that where there was concordance between parental and professional models of asthma, there were also direct positive effects on the quality of the adolescent’s medication regime (22).

Overall, illness perceptions were assessed in three ways in the studies reviewed here: by questionnaire, by interview (open or semi-structured), and by the use of methods based on patient drawings (25, 26). This method of using a drawing by the patient to reflect the image of the illness is a
### Table 1.—Summary of nine selected studies on asthma and illness perceptions.

<table>
<thead>
<tr>
<th>First author year country (ref.)</th>
<th>N patients mean age/age range setting</th>
<th>Theory/model</th>
<th>Assessment of illness perceptions</th>
<th>Dependent variable(s)</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Byer 2000 UK (16)</td>
<td>64 40 Primary care</td>
<td>Self-Regulation Theory</td>
<td>IPQ (Illness Perception Questionnaire)</td>
<td>Adherence</td>
<td>Illness perceptions predict adherence</td>
</tr>
<tr>
<td>Clarke 1997 UK (17)</td>
<td>36 ~ 8 Home and Out-patient Department</td>
<td>Health education</td>
<td>Inside-the-Body Test (drawing)</td>
<td>Knowledge of asthma and body</td>
<td>Asthma patients do not draw more body parts than non-asthma patients</td>
</tr>
<tr>
<td>Cohen 2003 USA (18)</td>
<td>160 16 Public high school</td>
<td>Self-management</td>
<td>Questionnaires: Anxiety, Control, Embarrassment, Optimism</td>
<td>Use of asthma medication</td>
<td>Anxiety (high), Control (low), Consequences (high) associated with poor self-management</td>
</tr>
<tr>
<td>Halm 2006 USA (14)</td>
<td>198 50 Inpatient department</td>
<td>Self-Regulation Theory</td>
<td>Interview on illness beliefs</td>
<td>Adherence</td>
<td>“No symptoms, no asthma”</td>
</tr>
<tr>
<td>Horne 2002 UK (19)</td>
<td>100 50 Primary care</td>
<td>Self-Regulation Theory</td>
<td>IPQ BMQ (Beliefs about Medicines Questionnaire)</td>
<td>Adherence</td>
<td>Illness beliefs and treatment beliefs predict adherence</td>
</tr>
<tr>
<td>Jessop 2003 UK (20)</td>
<td>330 17–87 Primary care</td>
<td>Self-Regulation Theory</td>
<td>Beliefs about Asthma Questionnaire [Identity; Cause; Time-line; Consequences; Care-control; Emotional representation]</td>
<td>Adherence</td>
<td>Illness perceptions predict adherence</td>
</tr>
<tr>
<td>Paterson 1999 NZ (21)</td>
<td>182 (35 with asthma) 7–14 School</td>
<td>Self-Regulation Theory</td>
<td>Structured interviews</td>
<td>Degree of sophistication of illness representation</td>
<td>Asthma patients have more sophisticated illness perceptions than non-asthma controls</td>
</tr>
<tr>
<td>Yoos 2007 USA (22)</td>
<td>228 Inpatient department</td>
<td>Self-Regulation Theory</td>
<td>Semi-structured interviews</td>
<td>Illness beliefs</td>
<td>Major differences in models of asthma between parents and health care providers</td>
</tr>
<tr>
<td>Zayas 1999 USA (23)</td>
<td>81 13–82 Open population</td>
<td>Self-management</td>
<td>Open question “What do you think asthma is?”</td>
<td>Quality of asthma care</td>
<td>Biomedical vs. biopsychosocial views on asthma</td>
</tr>
</tbody>
</table>
particularly interesting development in assessment. Broadbent et al. (27) have demonstrated how the size of the hearts drawn by myocardial infarction patients can successfully predict return to work and participation in cardiac rehabilitation programs, even after controlling for objective measures that reflect severity of the patients’ medical conditions (27). In asthma, assessment of illness perceptions using drawings has been used only very occasionally. Clarke et al. asked young asthmatics to draw “asthma” and found no differences between asthmatic and non-asthmatics in detail of their drawings (17). This seems an area that deserves further study, given that the findings reported by Broadbent et al. (27) and the opportunity afforded by the drawing method to elegantly avoid problems of circularity associated with the highly prevalent use of self-report variables as both predictors and outcomes in behavioral research.

In the studies reviewed here, respondents were selected from the open population, primary care settings, outpatient departments, and inpatient departments and reflected a wide range of severity of asthma. As such, the studies provide a breadth of coverage that strengthens the external validity of the review.

**DISCUSSION**

This review of empirical studies on illness perceptions in patients with asthma (and in one study, their parents) reveals that the area now benefits from a developed body of knowledge. All studies either explicitly used the framework of the Common Sense Model of Leventhal et al. (12), or else drew heavily on it. In six of the nine studies, the sample size exceeded 100 participants, which bolsters the internal validity of the research. The studies applied a variety of methods to assess illness perceptions: psychometrically standardized questionnaires (such as the IPQ or the IPQ-R), structured or open-ended interviews, and methods based on patient drawings. The findings reported here appear consistent with those produced by a meta-analysis on illness perceptions in chronic somatic diseases by Hagger and Orbell (13) in the way illness perceptions were associated with various outcomes across various domains. Especially striking is the repeated finding that patients are liable to adopt an episodic or acute illness model of asthma (rather than more accurately considering asthma to be a chronic condition), which serves to discourage patients from properly adhering to anti-inflammatory medication, from long-term monitoring of pulmonary function and from adequate self-management behavior.

A relatively new development in Common Sense Model research and application is the extension of investigations to include the exploration of perceptions relating to treatment (28). The possibility of an “Extended Common Sense Model” has been put forward in particular by Horne et al. (19), who have proposed links between illness perceptions and treatment perceptions. In a major publication on this subject, these authors found meaningful associations between asthma patients’ views on the illness and its treatment and non-adherence (19). Developing this research further will be helpful in constructing applicable interventions. In our view, many asthma patients hold inaccurate perceptions of medication (for example, the belief that corticosteroids are dangerous to health and so should be avoided) that are important to change and that are directly amenable to interventions based on research that targets both illness and treatment perceptions. This principle is no better illustrated than by a recent study in the present journal, which examined the possible mediating role of asthma medication beliefs in the relationship between minority status and adherence to therapy (29). Similarly, also in the present journal, Main et al. demonstrated how negative affectivity mediated relationships between perceived asthma symptoms and use of inhaled corticosteroids in a New Zealand sample of asthma out-patients (30), a finding that has recently been corroborated by similar research in the Netherlands (31). The combination of illness and treatment perceptions inherent to the extended Common Sense Model offers a rich theoretical context for suggestions regarding research and application.

Similar findings to the ones we report here have been presented in reviews conducted in other disease contexts. For example, French, Cooper, and Weinman (32) reviewed the area of illness cognitions in coronary artery disease and found that illness perceptions of acute myocardial infarction patients predicted attendance at cardiac rehabilitation. According to the authors “patients who view their condition as controllable, as symptomatic, and with severe consequences, and who feel they understand their condition are more likely to attend” (p. 757). Hagger and Orbell (13) also provide a wealth of empirical evidence on the relevance of illness cognitions in patients with a range of chronic somatic disorders. In their meta-analytic review, they identified 45 studies on chronic somatic disorders that adopted the Common Sense Model. They report that, across the research, perceptions of strong illness identity were found to be significantly and positively related to the use of coping strategies based on avoidance and emotion expression. Overall, they interpret the meta-analysis to have supported “the theoretically predictable relations between illness perceptions, coping and outcomes across studies” (p. 141). It can be noted that while a number of Cochrane reviews on patient education and self-management in patients with asthma have been published, these have as yet only occasionally touched upon the topic of illness models (e.g., 6). It would appear that sufficient literature now exists to support a Cochrane review of asthma research that explicitly focuses on illness perceptions.

Given the findings reported here, it appears crucial that research continues to examine determinants of illness and treatment perceptions in patients with asthma from various age categories, of various levels of severity, and across health care settings and countries. Recently, French & Weinman offered the suggestion that in the assessment of illness perceptions, developing and applying disease-specific questionnaires or measures would be helpful in refining both illness perceptions research and interventions that aim at changing those perceptions (33). Further to the findings in the Hagger & Orbell meta-analysis, additional research is needed to examine the value of the concept of coping and its place within the Common Sense Model framework, with a view to ultimately developing intervention studies that aim at improving self-management skills of people with asthma.

Intervening to change perceptions of illness and treatment in asthma, and the study the effects thereof on various types of outcomes, comprise exciting subjects for research. In other patient categories, a number of such intervention studies have
been recently undertaken (e.g., Goodman et al., in patients with systemic lupus erythematosus [34]; Petrie et al. in myocardial infarction patients [15]), with quite encouraging results. In Petrie’s study, nurses were trained to elicit and change illness perceptions in myocardial infarction patients, which were found subsequently to be associated with improvements in medical outcomes.

Two fascinating studies of physicians offer potentially relevant illustrations in this regard. In the first, primary care physicians were trained to elicit and discuss illness perceptions and action plans with patients. In a randomized design, it was found that such training did enable physicians to successfully alter patient perceptions (35). In a follow-up study, the researchers found that the training served also to enhance the physicians’ communication abilities across a range of other domains (36), reporting that “after a brief training the family physicians were able to change their communication style in a way that allows for a more thorough consideration of patient self-management” (p. 327).

As such, physicians can apparently be taught to elicit, challenge, and change illness perceptions and to replace them with more effective self-management-oriented perceptions about behavior. Guidelines for physicians on asthma management, therefore, should ideally cover the concept of perceptions about asthma and treatment and offer suggestions on how to incorporate this knowledge into regular medical care.

In conclusion, there is expanding empirical support for the assertion that perceptions regarding asthma and its treatment are important influences on outcomes. As such, by spending time and attention exploring patients’ perceptions of their illness (and treatment), physicians have the opportunity to modify their approach to medical management in an evidence-based way. As described by Bodenheimer, traditional patient education is now being supplanted by approaches based on modern views on self-management (37). In the contemporary context, physicians no longer take the lead in medical consultations, but rather define the medical encounter in collaboration with their patients. Patients are taught how to self-manage their condition and are encouraged to adopt constructive illness perceptions and treatment beliefs that help shape constructive coping skills to attain a maximum quality of life. It would appear that this promotion of shared decision making in place of traditional patient education is one example of where the Common Sense Model makes particularly good sense, given our review and those of others (13).

In many ways, behavioral research in asthma has come along way over the past 50 years, advancing from very weak and unscientific beginnings (in which asthma was seen as entirely psychosomatic) to today’s more solid empirical approaches (which focus on evidence-based interventions). The study of illness perceptions offers a particularly promising basis for continuing this progress.

REFERENCES


APPENDIX

(“Lung Diseases, Obstructive”[MeSH] OR “obstructive pulmonary disease” OR COPD OR asthma OR asthmatic OR emphysema OR bronchitis OR respiratory OR pulmonary) AND (“illness perception” OR “disease perception” OR “illness perceptions” OR “illness representations” OR “illness representation” OR “meaning of illness” OR “patients perception” OR “patients perceptions” OR ((patients’[title word] OR patient[title word] OR patients[title word] OR illness[title] OR disease[title]) AND (perception[title word] OR perceptions[title word]))) OR (“Lung Diseases, Obstructive”[MeSH] OR “obstructive pulmonary disease”[title word] OR COPD[title word] OR asthma[title word] OR asthmatic[title word] OR emphysema[title word] OR bronchitis[title word]) AND (“illness perception” OR “disease perception” OR “illness perceptions” OR “illness representations” OR “illness representation” OR “meaning of illness” OR “patients perception” OR “patients perceptions” OR ((patients’[text word] OR patient[title word] OR patients[text word] OR patients[title word] OR illness[title] OR disease[title])) AND (perception[title word] OR perceptions[title word])))