

REVIEW ARTICLE

Illness Perceptions and COPD: An Emerging Field for COPD Patient Management

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Objective. Patients with chronic obstructive pulmonary disease have perceptions of their illness and its management that determine their coping behaviors (e.g., adherence, self-management) and, consequently, their outcomes. This article reviews the empirical literature on illness perceptions in patients with COPD to provide clinicians with information regarding the potential utility of incorporating illness perceptions into clinical COPD care. **Method.** A literature search in PubMed identified 16 studies examining associations between illness perceptions and outcomes in patients with COPD. **Results.** Seven of the 16 papers were from US authors, followed by 3 each from the UK and The Netherlands, and one study each from Australia, Canada, and New Zealand. The first study was published in 1983, and the numbers of patients per study ranged from 10 to 266. The illness perceptions were those delineated by two theoretical models (cognitive behavioral theory and the Common Sense Model), and they were assessed with open interviews and validated questionnaires. Outcomes were disability, quality of life, and psychological characteristics. The studies revealed clinically meaningful associations between illness perceptions and outcomes. **Conclusion.** Our review supports the incorporation of illness perceptions into clinical care for patients with COPD. The assessment of illness perceptions should be routine, similar to routine assessments of pulmonary function. Discussing and changing illness perceptions will improve COPD patients' quality of life and reduce their levels of disability. COPD-specific assessments ("diagnosis") of illness perceptions and COPD-specific intervention methods ("therapy") that help change inadequate and maladaptive illness perceptions are research priorities.

Keywords illness perceptions, patient-reported outcomes, quality of life, self-management, collaborative care in COPD

INTRODUCTION

Patient-reported outcomes (PRO) and quality of life (QOL) are not just buzzwords. The emergence of these concepts reflects the recognition among clinicians and others involved in health care that perceptual and behavioral factors shape the patients' responses to disease stimuli and, in so doing, affect the illness and its treatment. Taking these factors into account in the medical management of patients improves medical outcomes, whereas ignoring these phenomena is associated with lower patient satisfaction and poorer medical outcomes (1).

Clinicians who provide care for COPD patients often observe how illness severity (e.g., pulmonary function) fails to predict functioning and quality of life to a large degree. At the same time, a substantial body of research illustrates how COPD patients' perceptions of their symptoms, signs, and illness influence adherence behaviours that, in turn, determine function and quality of life (2).

Behavioral scientists have contributed, with varying degrees of success, to the medical management of patients with COPD. From a broad historical perspective, the following approaches can be discerned: psycho-analytic (1950–1970) (3), psychomaintenance (1970–1985) (4), quality of life (1980 –

present) (5), patient education (1985–present) (6), and self-management (1995–present) (7).

One of the most promising behavioral research approaches guiding education and self-management techniques for patients with chronic somatic disorders focuses on the central role of illness perceptions: the cognitions (ideas, views, and beliefs) that patients have about their symptoms and illness (8, 9). Illness perceptions are idiosyncratic representations of symptoms and illness, formed on the basis of personal and observed encounters with illness as well as information from medical sources (e.g., physicians and books) and from the "popular" media, friends, parents, the Internet, and fellow patients. Whether they are medically accurate, these representations critically shape the responses (coping behaviors) of patients and consequently, their outcome. For example, Scharloo et al. (10–12) demonstrated how illness perceptions determined quality of life, hospitalization, and medication use in COPD patients, even after controlling for duration and objective severity of COPD. Fischer et al. (13) reported on the role of illness perceptions of COPD patients in their adherence to participation in pulmonary rehabilitation. A recent meta-analysis on illness perceptions in patients with various somatic disorders also illustrated these effects (14).

Physicians also develop perceptions of their patients' illnesses based on their medical expertise, accounts of symptoms, and experiences provided by the patients and

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observations of illness progression in response to treatment. Irrespective of whether they are “objectively correct,” their illness perceptions determine decisions concerning the medical management of patients with COPD in dramatic ways. Wildman et al. (15) recently reported how unrealistic pessimism of physicians on the prognoses of COPD patients affected their decision about admitting (or not admitting) COPD patients to the Intensive Care department, with potentially lethal (and unjustified) consequences for the patients.

Given the apparent clinical relevance of illness perceptions in patients with chronic illness, we wanted to examine the status of illness perceptions research in COPD care. In the areas of cardiovascular medicine and oncology, 323 and 376 papers on this topic have been published to date; the search of “illness perceptions AND COPD” produced about a tenth of those numbers, with 33 papers identified [PubMed search, 2 April 2008]. With this article we want to introduce the concept of illness perception in the work of health care providers for COPD patients, examine the empirical evidence on this subject from studies of patients with COPD, and suggest research and clinical opportunities regarding the development and use of techniques for assessing and changing patients’ illness perceptions to improve medical outcomes in COPD patients.

METHOD

A systematic literature search of PubMed on “Illness perceptions and COPD” was conducted (the search strategy is given in the Appendix). The references in the identified papers were examined, and personal files of the first four authors (all currently involved in illness perceptions research in COPD patients) were checked manually. Studies had to be published in English and examine only patients with one diagnostic category (i.e., studies using samples of asthma and COPD patients combined were excluded). In addition to summarizing the outcome variables, we also outline the psychological theories or theoretical models that guided the study and the method(s) used to assess illness perceptions.

RESULTS

The 16 studies that fit the selection criteria are summarized in Table 1 (4, 10–12, 16–27). Of the studies included, 7 were conducted in the USA, with the UK and the Netherlands following with three studies each. The number of patients per study varied from 10 to 266.

Regarding the psychological model that guided the studies, the Common Sense Model (CSM: [8]) and cognitive behavioural theory were used most frequently. The Common Sense Model identifies key illness perceptions incorporated within mental representations of illness: Identity (illness label and symptoms), cause (factors responsible for its development; e.g., smoking, heredity, etc.), timeline (duration; e.g., as a chronic or acute condition), consequences (potential physical, psychological, and social outcomes; e.g., disability, social isolation), controllability (whether and how the illness might be controlled or cured), and emotional representations (perceptions of anxiety, depression, and other emotional reactions induced by the illness). The model also outlines the relationships between illness perceptions, cop-

ing efforts, and outcomes. Cognitive behavioral theory and therapy focus on how thoughts, beliefs, and cognitions relate to behavior; maladaptive behavior is addressed by eliciting and changing problematic cognitions held by patients (28).

Illness perceptions were assessed with questionnaires and interviews. As can be seen in the fifth and sixth columns of Table 1, the outcome variables used most frequently were either observable (e.g., walking distance) or self-report (e.g., depression) variables. The major results of the studies reveal statistically significant and clinically meaningful associations between illness perceptions and various outcomes. Overall, illness perceptions that reflect attributing many symptoms to COPD (“identity”), perceiving a low sense of control (“control”), and strong emotional perceptions (anxiety, depression, catastrophizing) appear to be associated with poor outcomes. Consistent with reviews of illness perceptions research within other illness categories, a higher sense of control and self-efficacy and more stable emotional representations appear to be associated with more favorable outcomes (8).

DISCUSSION

An important finding in this review was that the role of illness perceptions has been evaluated fairly extensively in patients with COPD, albeit not to the same extent as has been done for cardiovascular diseases and cancer. Given the relatively young age of the theoretical models underlying the concept (e.g., the Common Sense Model [8, 29]), it is encouraging to see the growing attention to the relevance of illness perceptions in clinical care for patients with COPD.

The results of our review indicate that illness perceptions are associated with various categories of outcomes, i.e., functional status and disability, psychological outcomes (i.e., depression, anxiety), and quality of life. This is consistent with results in studies on illness perceptions in other patient populations. In a meta-analysis, Hagger and Orbell (14) reported comparable findings on associations between various dimensions of illness perceptions and similar outcome measures in patients with, for example, breast cancer or myocardial infarction.

We limited the literature review to empirical papers published in English. A more important limitation in the review pertains to the often cross-sectional nature of the studies included in the review. Prospective designs are called for to examine which illness perceptions prospectively predict which outcome measures.

Our review has several implications for further research and clinical care in patients with COPD. As suggested recently, developing and assessing COPD-specific illness perceptions will contribute significantly to the refinement and evolution of the research in this area (29, 30). Also, in choosing outcome measures, we encourage researchers to use observable behaviors, and ideally those that can be verified through objective measures or unbiased observers, rather than or in addition to self-reports. As Coulter and Ellins (31) write, after reviewing the literature on the effectiveness of strategies for informing, educating, and involving patients, these issues do not simply reflect “the ‘touchy feely’ aspects of health care, with no scientific basis and little relevance to the quest for excellence in clinical care” (p. 24), but rather, “a substantial evidence base exists for building strategies to strengthen

TABLE 1.—Summary of studies on illness perceptions in COPD-patients.

| First author Year Country [ref] | N pts Age (mean ± SD) | Theory/Theoretical model | Assessment of illness perceptions | Outcome variable(s) | Results |
|---------------------------------|------------------------|--------------------------------------|---|---------------------------------------|--|
| Atkins, 1984 USA (16) | 76 (65 ± 8) | Cognitive-behavior modification | Open interview; Monitoring of self-statements | Health status Walking distance | More goal oriented self-statements lead to better health status and walking distance |
| Dowson, 2004 NZ (17) | 39 (71 ± 7) | Self-management | Interviews on health locus of control (self, health care provider) | Self-management behavior | Low perceived control associated with poor self-management |
| Falter, 2003 Canada (18) | 50 (70 ± 8) | Self-efficacy | Interview and questionnaire on perceptions of independence, self-efficacy | Disability | Low perceived independence associated with higher disability |
| George, 2005 Australia (19) | 266 (71 ± 8) | Common sense model (self-management) | Questionnaire on health beliefs (identity, control, etc.) and health behaviors | Adherence (self-report) | Adaptive health beliefs linked to better adherence |
| Gurney-Smith, 2002 UK (20) | 30 (67 ± 8) | Cognitive-behavior Modification | Questionnaire on catastrophizing cognitions and agoraphobia | Anxiety | Catastrophizing associated with higher anxiety about COPD |
| Insel, 2005 USA (21) | 38 (70 ± 8) | Common sense model (self-management) | Perceived experience of breathlessness; awareness of breathing; worry | Chronicity | Awareness and worry leads to more chronicity |
| Kinsman, 1983 USA (4) | 146 (63 ± 9) | Psychomaintenance | Bronchitis Emphysema Symptom Checklist (BESC) | Disability | Higher BESC scores associated with higher disability |
| Lacroix, 1991 USA (22) | 31 (54 ± 16) | Patient education | Schema Assessment Instrument assessing accuracy of patients' knowledge | Disability | Higher knowledge linked with less disability |
| Morgan, 1983 UK (23) | 50 (60 ± 7) | Psychomaintenance | General Health Questionnaire; Multiple Affect Scale | Disability | Maladaptive emotional representations associated with higher disability |
| O'Neill, 2002 USA (24) | 21 (67 ± 10) | Self-Regulation Model | Open interview assessing illness representations | Coping | "Causes" and "consequences" associated with coping |
| Scharloo, 1998 NL (10) | 80 (64 ± 8) | Self-Regulation Model | Illness Perception Questionnaire (IPQ) assessing identity, timeline, emotional attributions, consequences, control/cure | Daily activities score; SF-36 | IPQ-scores are associated with daily functioning |
| Scharloo, 2000 NL (11) | 64 (64 ± 8) | Self-Regulation Model | IPQ | Coping, Quality of Life (QOL) | Illness perceptions predict QOL and visits to outpatient clinic, prescribed medication |
| Scharloo, 2007 NL (12) | 171 (66 ± 10) | Self-Regulation Model | Illness Perception Questionnaire – Revised (IPQ-R) | Coping, Quality of Life | Illness perceptions predict QOL: fewer perceived symptoms, less strong emotional response to COPD are associated with better QOL |
| Seamark, 2004 UK (25) | 10 (75 (SD not given)) | Patient education/palliative care | Open interview, interpretative phenomenological Analysis | Patients and partners experience loss | Social isolation and decline of social activities are associated with maladaptive coping and passive illness perceptions |
| Siela, 2003 USA (26) | 97 (65 ± 11) | Self-efficacy | Questionnaires assessing dyspnea perceptions, self-efficacy, functional status | Functional Performance Index (FPI) | Self-efficacy and dyspnea perceptions predict FPI-scores |
| Stehr, 1991 USA (27) | 33 (66 ± 9) | Coping | Questionnaires assessing illness beliefs | Admission to hospital relapse | Illness beliefs (control, identity) predict relapse |

patient engagement" (p. 27). Engaging patients by definition involves exploring their perception of their illness.

The clinical implications of our review point to the opportunities for intervention through the application of cognitive behaviorally inspired programs where illness perceptions are the core targets of the intervention. Atkins et al. (16), with notable prescience, applied this format already in 1984, with impressive results: Maladaptive illness perceptions ("I can't walk very far without getting short of breath, so what's the use?") were elicited, addressed and changed ("this walking is uncomfortable, but I can handle it. Soon I'll be able to walk farther"), which led to significant improvements in exercise capacity and quality of well-being (16). Petrie et al. (32) demonstrated how eliciting and changing maladaptive illness perceptions in myocardial patients resulted in higher rates of participation in cardiac rehabilitation programs, fewer symptoms of angina, and earlier resumption of work compared with a regular care control condition. A few related intervention studies also illustrate the clinical usefulness of this approach (33, 34). Women with early stages of cervical can-

cer were more motivated to give up smoking once they had a coherent perception of how smoking was associated with a physical process "downstairs"(sic; p. 419), i.e., cervical cancer (33). Patients on hemodialysis had a higher intention of adhering to phosphate binding medication once they witnessed how this medication solidified water in a glass mock-up stomach ("So that's what they mean by binding!") (34). Incorporating illness perceptions, assessing these beliefs routinely, and addressing maladaptive beliefs seems to be an evidence-based clinical implication of our review. Clinicians may consider including questions designed to elicit illness perceptions during patient interviews. Examples of questions include: (1) What do you think is wrong? (Identity); (2) What do you think will happen in the future? (Consequences); (3) What do you think caused your COPD? (Cause); (4) How do you think your treatment will affect your COPD? (Control); (5) How long do you think your COPD will last? (Timeline); and (6) What concerns about your condition do you have? (Emotions/Worry). Incorporating some of these or similar questions at appropriate times during patient

interviews may help clinicians identify important misconceptions and barriers to treatment adherence.

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APPENDIX

Search Strategy

“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'[title word] OR patient[title word] OR patients[title word] OR illness[title word] OR disease[title word]) AND (perception[text word] OR perceptions[text word]))) OR ("Lung Diseases, Obstructive"[MeSH] OR "ob-

structive 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[text word] OR patients[text word] OR illness[text word] OR disease[text word]) AND (perception[title word] OR perceptions[title word])))