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REVIEW

50 Years of psychological research on patients with COPD – Road to ruin or highway to heaven?

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Received 19 March 2008; accepted 30 August 2008

Available online 19 October 2008

KEYWORDS

COPD;
Psychology;
Self-management;
Patient involvement;
Quality of life;
Research agenda

Summary

Objective: To review the topic of behavioural research on patients with COPD over the past 50 years in order to help inform clinical management and future research on psychosocial aspects of COPD.

Method: Narrative literature review.

Results: Nine orientations in behavioural research on COPD patients are identified and concisely examined: psychoanalytic approach, psychosomatics, neuropsychology, quality of life, psychomaintenance, patient education, coping and illness cognitions, self-management, and collaborative care. These approaches form a historical sequence of psychosocial perspectives on COPD, of successively increasing utility in COPD research and care.

Discussion and conclusion: In the past 50 years behavioural research on COPD patients has evolved considerably. Over time, a trend for the patient to become the central actor in the management of the illness is discernable. Evidence-based reviews indicate that self-management offers COPD patients effective options for managing their illness, leading to positive outcomes such as reduced frequency of hospitalization, greater exercise tolerance, and enhanced quality of life. Future research should focus on how self-management skills can be incorporated formally into medical care. In addition to offering suggestions on how clinicians may be instrumental in improving self-management behaviour in COPD patients, and thereby improve care outcomes, we highlight the importance of gaining insight into the perceptions of

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patients of their own situation, and incorporating a respect for patient perspectives into the philosophy of care.

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Introduction

*Medicine is a social science in its very bone and marrow.*¹

Recent research on the psychological and social consequences of COPD underlines the substantial adverse impact of this respiratory disorder on patients' well being, work absenteeism, depression and anxiety, and sexual quality of life, as well as on the well being of patients' spouses and families and of wider society.^{2–4} Increasingly, modern medical care for patients with chronic illness involves self-management and shared decision making.^{5,6} International guidelines on diagnosis, management, and prevention of COPD pay particular attention to the incorporation of patient education into care and to the improvement of patients' quality of life.⁷ In *Respiratory Medicine*, this trend is illustrated by the increasing frequency with which papers on self-management, quality of life, and patient involvement in developing guidelines are being published.^{8,9}

However, the contribution of psychological research to respiratory disorders is not always widely acknowledged. For example, in a fascinating historical review ("Summing up 100 years of asthma") recently published in this journal, Diamant and colleagues make no reference to behavioural research.¹⁰ In a corresponding review of COPD ("One hundred years of COPD"), the authors do discuss the psychosocial ramifications of pulmonary rehabilitation, but the focus of the paper remains largely on pharmacological management of patients.¹¹ This stands somewhat in contrast to a number of other patient categories, where medical care tends to pay more explicit attention to psychosocial aspects of being ill in both diagnostic and therapeutic contexts. For example, guidelines on breast cancer or diabetes

customarily encompass issues such as chemotherapy-induced nausea and anxiety and the use of questionnaires to assess anxiety about self-injecting insulin, with suggestions for both physicians and patients on how to cope with these events and optimize quality of life.^{12,13}

With the present paper, we aim to locate developments in the area of behavioural research on patients with COPD in a concise historical perspective. From this review of the history and current status of psychological research on patients with COPD, we offer suggestions for future research and for incorporating psychosocial aspects of COPD into clinical care. As Kiley and Nabel recently noted when discussing a trial on pharmacological management of the condition, "COPD is finally moving from obscurity to prominence, and so it should"¹⁴ [p. 867]. It is our intention to present an analogous position with regard to the psychosocial aspects of the diagnostic and therapeutic phases of the medical management of COPD: in terms of medical understanding, such psychosocial factors are emerging from obscurity and entering into the limelight; given their potential to benefit patients with COPD, this is as it should be.

Method

We base our paper on a narrative review of literature. The search strategy below was used in PubMed to identify papers on the subject of this review.

((ASTHMA* or EMPHYSEMA*) and (PSYCHOL* or REHABIL*)) or (BRONCHITIS and PSYCHOLOG*) or (((CHRONIC OBSTRUCTIVE PULMONARY" or "CHRONIC OBSTRUCTIVE LUNG") and PSYCHOLOG*).

In addition, previous reviews and personal files were examined.^{15,16}

Results

Across these publications, we distinguished nine phases in the history of psychological research on COPD patients (see Fig. 1) with a general tendency for theoretical papers to precede empirical reports. As in any historical categorization, changes from one phase to another tend to be gradual. Therefore, the timeline represents a broad-brush depiction of a quite long line of research, although external validity for our nine phases is provided by their correspondence with the histories of behavioural medicine approaches to other chronic physical disorders.^{17,18}

Psychoanalytic views

In the early decades of the twentieth century, psychoanalysis provided the dominant psychological approach to patients with selected physical disorders such as asthma, hypertension, and diabetes. In this tradition, psychological factors were viewed as the primary causes of physical symptomatology. While many respiratory conditions were interpreted in this way,¹⁹ COPD tended to be an exception, most probably because in COPD the smoking of tobacco was such an obvious non-psychological determinant of respiratory problems. In addition, it is probable that therapeutic pessimism and social stigma led some psychoanalytically oriented psychiatrists and psychologists to exclude COPD patients from their theorizing and therapeutic efforts. This was often the case with regard to patients with so-called 'HOUND' characteristics (i.e., patients who are perceived as being *humble, old, unattractive, non-verbal and dull*), who in psychotherapy research have tended to be relatively underserved at the expense of patients with 'YAVIS' characteristics (i.e., those who are perceived as young, attractive, verbal, intelligent and successful).²⁰

Nonetheless, psychotherapeutic methods inspired by psychoanalytic views have been studied empirically with COPD patients.²¹ In a randomized controlled study (which was a major logistical achievement in itself), COPD patients from an out-patient department were randomized to four groups: (1) a psychoanalytic psychotherapy group, in which

patients received psychotherapy from experienced psychoanalysts; (2) a supportive/non-analytic therapy group, in which therapy was provided but psychoanalytic transference interpretations were withheld; (3) a nurse-led patient support group, in which a nurse without any psychotherapeutic training led the patient through discussions on their condition; and (4) a control group, who submitted to weekly laboratory tests instead of therapy. All groups underwent eight 45-min sessions. The results indicated that patients in the nurse-led patient support group benefited most in terms of reduced shortness of breath on 6-month follow-up. These essentially positive effects of the most down-to-earth condition suggested that, in COPD, formal psychotherapy was less useful than other types of formal interpersonal support (thereby signaling at an early stage the future development of other approaches to psychosocial intervention, which will be discussed later).

The psychoanalytic approach to patients with COPD was no doubt inspired by the wish of care providers to understand and help patients in managing their illness. The approach aspired to promote a comprehensive view on physical health, in which psychological and social determinants are considered to be of fundamental importance. As such, the approach presented a fascinating and thought-provoking addition to the diagnostic and therapeutic repertoire of health-care providers caring for patients with COPD. However, over time, psychoanalytic approaches have been found to have been over-reliant on subjective clinical judgment and speculation, and have largely failed to attract empirical support in research studies. At the beginning of the 21st century, therefore, one must conclude that the theoretical and empirical elements of the psychoanalytic approach are unlikely to have a place in the care for persons with COPD.

Psychosomatics

Rather than attempting to implicate deep intra-psychic conflicts in the etiology of COPD, a number of investigators sought to establish whether COPD could be linked to more superficially accessible psychological traits and states,

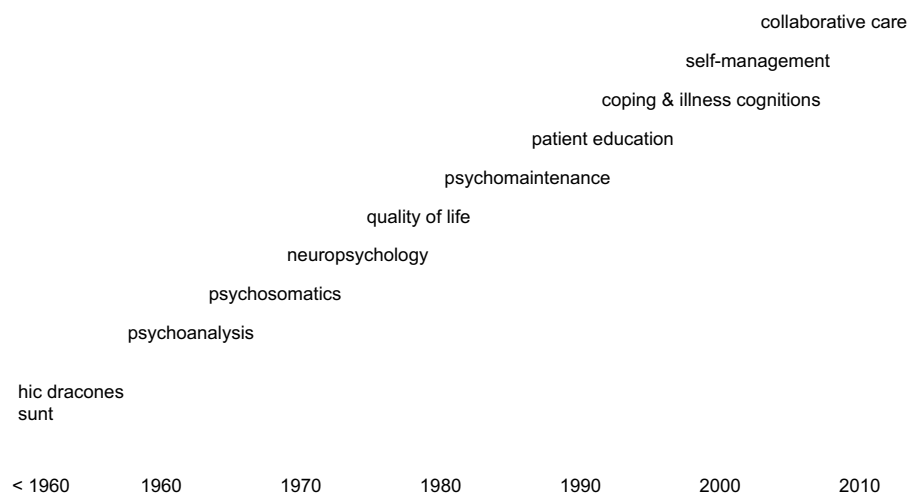


Figure 1 Theoretical approaches to behavioural research and clinical care for patients with COPD, 1960 – current.

thereby elucidating likely psychosomatic influences. The very first empirical study on personality characteristics of COPD patients was published in 1961.²² The authors examined a sample of 33 inpatients with "primary obstructive emphysema". They used the Szondi test, a psychological measure popular at the time, to assess basic personality traits. The authors report in this sample of COPD patients "the presence of [the following] traits in the emphysema group...hypersensitivity, marked passivity...and emotional immaturity" (p. 607–8).

In a similar vein, Agle and Baum explored the psychosocial consequences of COPD in a small sample ($n = 23$) of males in a rehabilitation setting. Using psychiatric interviews, the authors found a disturbingly high prevalence of anxiety, depression, alcoholism, sexual dysfunctions, and various psychiatric psychopathologies (e.g., "paranoid states").²³

It should be noted how the approach of linking personality characteristics to COPD continues within contemporary research, albeit in a somewhat evolved form. A recent paper by Hynninen and colleagues is an illustration: the authors review 81 studies on psychological characteristics of COPD patients, and report on the importance of characteristics such as depression, anxiety, personality disorders, panic-fear, and self-esteem, and on their interactions with physical symptoms.²⁴ The authors quite rightly state that further research on this topic is warranted in order that they can be considered in the clinical encounter.

Neuropsychology

From the 1980s on, psychologists specializing in neuropsychology became a new group of behavioural scientists studying COPD, often in collaboration with respiratory physicians and psychiatrists. Their efforts were directed at investigating whether the chronic and progressive airway obstruction seen in COPD might contribute to adverse hypoxic impact on the brain to an extent that becomes manifest in cognitive function. In a controlled study, Prigatano and colleagues established how COPD in its more severe forms is indeed associated with neuropsychological impairments, with patients exhibiting impaired abstract reasoning, language ability, and memory, for example, compared to matched non-patients.²⁵ In follow-up investigations, this research group established that associations between level of hypoxia and degree of neuropsychological disturbances appeared to be linear, with greater impairment associated with greater COPD-related hypoxemia.²⁶ In these studies, the researchers statistically controlled for depression and task motivation, strongly suggesting that the observed effects were due to organic impairment. More recent research in COPD patients with end-stage pulmonary disease revealed severe degrees of impairments on several neuropsychological tests,²⁷ with scores on the MMPI indicating a diversity of comorbid somatic complaints (e.g., depression, hypochondriasis). In a review of the relevant literature, Zieliński reports how long-term oxygen therapy can be used to improve cognitive function and emotional status in COPD patients.²⁸ Overall, neuropsychological research on patients with COPD reflects an important aspect of behavioural research in these patients, requiring specific knowledge and skills. As well as impacting on patients' well being, the emergence of cognitive impairment

in COPD has implications for clinical practice, in that a patient's capacity to engage with medical advice may be compromised in general or specific ways.

Quality of life

Clinicians in respiratory medicine have increasingly observed the disparity between objective measures of treatment effects and subjective measures reported by patients. Changes (or lack of changes) in pulmonary function following pharmacological treatment do not translate well into changes in subjective well being. In the very first paper in respiratory illness research to focus on quality of life (QOL) as a specific outcome, Stewart et al. reported positive long-term effects on QOL of continuous oxygen therapy in a small sample of patients with severe COPD.^{29,30} QOL was operationalized using patient diary notes as well as self-reports on improvements in ability to perform daily tasks. The publication of standardized instruments to assess QOL in respiratory patients has been a breakthrough in this area, by enhancing the reliability and validity of such assessments.^{31,32} The two most common disease-specific QOL-scales focus on symptoms, activity, impacts, and total QOL,³¹ and dyspnea, fatigue, emotional function, and mastery,³² respectively, and have helped produce an extensive empirical literature. A PubMed search on 'COPD and QOL' (6 June 2008) produced 2132 hits, suggesting that the area of QOL and COPD is a field of scientific study in its own right (an example of a literature review is Schmier et al.³³). In QOL research, disease-specific QOL measures are frequently combined with generic QOL questionnaires, allowing comparisons of the COPD-sample with samples of healthy and/or ill persons with diagnoses other than COPD.³⁴ Overall, QOL has been found to have only a weak association with pulmonary function in COPD patients but, despite this, to predict mortality.³⁵ Looking back over the past 30 years of research, it is striking to observe how QOL has evolved in methodological terms: from a 'soft', 'subjective', secondary outcome measure to an important component in guidelines and research on clinical care, where patient-reported outcomes now have a central position.

Psychomaintenance

In Denver, Colorado, a research group in the National Jewish Hospital and Research Center established that among patients with respiratory disorders, illness behaviour and experiences (such as becoming irritable, worried, forgetful, or apathetic) determined length of hospitalization, frequency of rehospitalization, and strength of medication at discharge better than objective measures of illness severity.³⁶ This finding was established in inpatients with COPD after extensive research in this area on patients with asthma. The Bronchitis and Emphysema Symptom Checklist³⁶ was used to assess subjective symptomatology, covering symptoms, attitudes towards the illness and health-care providers, personality factors, and clinical characteristics. The investigation of such variables has led some researchers to consider a construct known as *psychomaintenance*, namely, "how psychological and behavioural factors maintain and increase both perceived severity and medical intractability of the illness once it has already

developed”³⁷ (p. 435). The fact that pulmonary function may be a less important contributor to care outcomes than illness behaviour and experiential/perceptual variables suggest clear avenues for therapeutic research. Interventions designed to modify illness behaviour may exert an impact on outcome variables such as those studied by the Denver group. One potential vehicle for such interventions is patient education.

Patient education

In the 1970s and 1980s, respiratory physicians and nurses started experimenting with providing patients with information on anatomy, physiology and pathology of COPD, on the assumption that more knowledge would lead to better outcomes. A photo in the 1971 Neff and Petty study³⁸ (p. 12) is highly illustrative: a white-capped nurse explains how lungs function by drawing a picture of a lung on a blackboard; four COPD patients on chairs passively watch this lecture, with a head-nurse looking on. However, making sure that COPD patients improve their knowledge about the disease is no guarantee of improvements in their illness behaviour or self-management skills.

Using a quasi-experimental design, researchers at Dartmouth Medical School provided a patient education intervention to COPD patients in a community in the northeastern United States, and compared pretest and posttest measures of health outcomes with those from a control community in a different state who received no education program. The intervention comprised six 2-h sessions COPD in which patients received information on basic respiratory anatomy and physiology, physical endurance, medications, nutrition and hydration, and related topics. Also, basic self-management skills were taught within these sessions. The results were similar to those of other studies on patient education and illness: a minor but statistically significant change in a measure of health perception (i.e., locus of control), but no significant gains on physical function, mental health, or social function.⁴⁷ Similar findings have been reported in European research.⁵⁰ In a systematic review on patient education research, Blackstock and Webster conclude that “didactical educational intervention for the COPD population appeared to have minimal effect on health outcomes including quality of life, health-care utilization, exercise capacity or lung function and is therefore not the educating delivery method recommended”³⁹ (p. 703). Patient education has been shown to improve knowledge. However, it is crucial to understand that the effects of patient education as a single intervention on patient-reported outcomes, such as quality of life, activities of daily life or feelings of social isolation, are very limited. Producing fliers, videos, or attractive websites with patient information is not sufficient to improve COPD patients’ QOL, perhaps because of the passive nature of interaction with them by patients. Interventions that seek to engage patients in particular patterns of thought might be more suited for this purpose.

Coping and illness cognitions

Clinicians will be directly familiar with the fascinating variety in how individual COPD patients cope differently

with their illnesses. These differences seem not to be influenced greatly by objective characteristics of COPD but rather by how patients interpret and experience their symptoms and their consequences. In behavioural health research, the term *coping* is used to refer to the cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person⁴⁰ (p. 141). The crucial element here is “appraisal” (the subjective meaning given by a patient to COPD and its consequences). Personal experiences and learning histories, personality characteristics, illness cognitions, and social influences all serve to determine coping, but are likely to manifest themselves in unique ways for each individual patient. This may help explain why patients with identical objective severity of COPD differ in managing their illness. Psychometrically, coping with COPD is usually assessed with validated generic and/or disease-specific questionnaires. Based on this approach, coping has been found to determine the course of COPD to some degree: Scharloo et al. found coping to predict number of visits to an out-patient department better than objective measures of COPD severity.⁴¹ Coping is closely tied in with how patients make sense of symptoms and treatment. One major theory in behavioural medicine, the Common Sense Model,⁴² suggests that specific cognitions about illness play important roles in this process. In particular, cognitions concerning how patients conceptualize the causes, consequences, timeline, identity, and curability/controllability of their illness have been found to have particular predictive validity. Recent research demonstrates that illness cognitions influence coping in a range of medical conditions, and specifically how illness cognitions impact on outcomes in COPD.^{43,44}

Coping and illness cognitions represent a turning point in COPD research, from a purely behavioural approach to one that emphasizes the central role of the subjective reality of the patient’s appraisal, experience, and management of his/her illness in shaping outcome of medical care of COPD. Also, coping and illness cognitions are central elements in two important contemporary approaches in medical care for patients with COPD, which are discussed in our last two sections: namely, self-management and collaborative care.

Self-management

One of the most recent focuses within behavioural research on COPD is on self-management. Self-management pertains to “the ability of patients to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition” while also encompassing the ability to monitor one’s condition and “to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life”⁴⁵ (p. 178). It is clear that self-management encompasses very much more than patient education or than trying to make patients more knowledgeable. Self-management implies involving patients in the care they receive and encouraging them to become active partners in managing their illness. A quite extensive body of knowledge is available that supports the effectiveness of self-management approaches with COPD patients.

In a review on behavioural interventions in patients with advanced COPD, Bourbeau concludes that "disease-specific self-management can improve patients' health status and reduce physician visits and hospital use"⁴⁶ (p. 311). Bourbeau defines self-management in a way that behavioural scientists endorse, and which derives from views on collaborative care⁴⁸ (an area of interest in its own right; see below), mentioning health promoting activities, interacting with health-care providers, adherence, monitoring emotional status, making management decisions, and maintaining self-esteem and supportive relationships with others. It is important to distinguish between the term "self-management" as discussed in some medical contexts (such as treatment guidelines⁷ or in early studies of patient's self-management) on the one hand, and the defined term as it has been used latterly by behavioural scientists on the other (cf. Ref. 46). Howland's study, for instance, adopted a somewhat narrow description of self-management that more resembled patient education, and which turned out to be associated with only a small number of quite distal psychological outcomes.⁴⁷ In contrast, in a more recent study on self-management by a research group from Montreal, the investigators found that a deliberative and action-oriented self-management intervention impacted positively on both short- and long-term hospitalization.⁴⁹ The intervention in this randomized clinical trial in patients with severe COPD combined traditional patient education with a disease-specific self-management and action-planning intervention. As well as reductions in hospitalization, the study reports significant gains in other relevant outcomes, including fewer emergency visits to hospital.

When the term "self-management" is used in treatment guidelines⁷ it often refers narrowly to symptom perception, compliance with medication, and using action plans for exacerbations.⁷ This is exemplified by, for instance, Gallefoss who in a study on patient education conceptualized self-management in this somewhat biomedical sense: teaching the skills of recognizing potential exacerbations and managing them via medication, self-monitoring of pulmonary function by the patient, and providing patients with action plans that specify which medication to take under which circumstances and when to consult a physician.⁵⁰ However, as was outlined with regard to patient education, a focus on skills, cognition, and reasoning as well as on disease knowledge, is required for full-blown self-management to be effective

The research literature on self-management interventions for COPD is large enough to form the basis for Cochrane Reviews. The most recent such review concludes that "it is likely that self-management education is associated with a reduction in hospital admissions with no indication for detrimental effects in other outcome parameters".⁵¹ Given the quite strict study selection criteria and statistical analyses applied in Cochrane Reviews, this must be evaluated as a rather positive statement on the efficacy of self-management in COPD.

In the context of self-management in patients with chronic illness generally (and not just COPD), the newest research and clinical applications are largely based on the principles of cognitive-behavioural therapy. Within this paradigm, cognitions of patients are elicited and, if indicated, changed with the active involvement of the patient

into more constructive and adaptive patterns of thought. Empirical research shows that such changes are associated with a number of improved outcomes, such as earlier return to work, resumption of sexual activities, and fewer symptoms.⁵² In COPD, the study by Atkins et al. is groundbreaking in this regard. In this randomized control trial, maladaptive and adaptive self-statements (e.g., such illness perceptions as "I can't walk very far without getting short of breath, so what's the use" and "This walking is uncomfortable, but I can handle it. Soon I will be able to walk farther") were addressed⁵³ [p. 594]. Patients given a cognitive-behavioural intervention had a higher exercise capacity and quality of well being afterwards, compared to the patients in other experimental conditions. Our group published work in a similar vein, focusing specifically on demonstrating how illness perceptions are associated with coping and quality of life.⁴³ The specific role of illness perceptions in COPD is discussed in detail elsewhere.⁴⁴ It would appear that more research in the area of self-management in COPD patients is called for in order to explore this area with a much greater degree of detail.

In pulmonary rehabilitation programmes, the contribution of behavioural scientists and clinicians is nowadays no longer debated, and educational interventions, self-management programmes, and psychosocial support have each become integral components of such programmes.⁵⁴ In their Cochrane Review, Lacasse and colleagues conclude that "rehabilitation relieves dyspnea and fatigue, improves emotional function and enhances patients' sense of control over their condition"⁵⁵ [p. 1–2]. Further, in this context the importance of illness perceptions was recently underlined,⁵⁶ as was the subject of sexuality.⁵⁷ The increasing recognition that disease outcomes are influenced by biological, psychological, social, health-care, and environmental factors has led to some discussion of the need for self-management and other interventions to be conceived of within a framework of collaborative care.

Collaborative care

Von Korff and colleagues maintain that modern medical management of patients with any chronic physical illness requires collaborative care, which they describe as involving the following principles: (a) that illness management skills are learned and behaviour is self-directed; (b) that motivation and self-confidence are important determinants of self-care; (c) that the social environment (including the family, workplace, and health-care system) can either support or impede self-care; and (d) that monitoring and responding to changes in disease state and symptoms, and in emotions and functioning, improve illness adaptation⁴⁸ [p. 1097–8]. Empirical support for this comprehensive approach in COPD patients is still scarce, but nonetheless promising. After a systematic review of the effects of chronic disease management on QOL in COPD patients, Adams et al. conclude that the chronic care model is associated with lower rates of hospitalizations and ER visits and a shorter length of stay compared with control groups.⁵⁸ This conclusion is echoed in Niesink et al.'s systematic review on chronic disease management on QOL in COPD patients,⁵ although both research groups stress the need for further research.

Discussion

The past 50 years have seen an impressive development of the area of psychological research on patients with COPD. In terms of assessment (or “diagnosis”), consideration of the problems of COPD patients has evolved from attempting to measure unconscious conflicts or personality characteristics in the psychoanalytic and psychosomatic approaches, to assessing illness perceptions and self-management skills or sexuality in the self-management approach. In terms of therapeutic interventions (or “treatment”), attention has evolved from group psychotherapy and becoming informed about alveoli to learning about how to perceive the first signs of an exacerbation and to discuss with one’s partner the psychosocial consequences of COPD.

In terms of its sophistication, utility, and applied relevance, behavioural research in COPD has in the past decades caught up considerably with that conducted with regard to other illnesses. A recent review of self-management approaches in asthma, diabetes, and arthritis, published in *The Lancet*, concluded that self-management is an important component of the arsenal with which clinicians and patients can improve the quality of medical care.⁵⁹ Cochrane Reviews on self-management interventions in COPD, and other review papers on this topic, have concluded that self-management does have positive effects on outcomes such as number of hospitalizations and quality of life.^{51,55,57}

Fig. 1 is a graphical summary of 50 years of behavioural research on COPD: it illustrates how the patient with COPD has increasingly become the central person in the process of medical (and behavioural) care over the decades. It can also be deduced how the shift in outcome measures in COPD-care reflects this change too: from FEV₁ and 6-min walking tests, to quality of life scores and self-management skills.

It has been our aim to give the reader a concise overview of the behavioural approaches to patients with COPD that have been used in the past 50 years. In this review we gave attention to interventions aimed at impacting on various outcome measures. This delivery to patients of interventions should not distract from the importance of listening to patients when they talk about their illness. By being receptive to patients’ reportage, health-care providers may learn about what it is like to live with COPD and to understand the existential reality in which these patients are immersed.⁶⁰ Respecting and understanding the nature of the suffering of patients with COPD (or any other medical condition, for that matter) are part and parcel of being a dedicated physician and effective health-care provider.⁶¹

Compared to other major illnesses such as cardiovascular disorders or cancer, the application of self-management to COPD warrants much more research attention. For example, while a 6 June 2008 PubMed search produced 4767 hits for ‘self-management and cardiovascular disorders’ and 4937 for ‘self-management and neoplasms’; a search for ‘self-management and COPD’ produced only 456 hits. Given that self-management approaches are widely acknowledged as being useful in cardiovascular medicine and oncology, the area of COPD appears to present considerable potential. Gross et al. appear to

endorse this view when they note the wide disparity between prevalence of COPD in the population and the level of research funding directed towards it by the NIH.⁶²

In addition to psychological research on patients with COPD, we suggest three additional avenues for future research. Firstly, more research could focus specifically on partners of patients with COPD, as opposed to the patients themselves, as partners are centrally important in supporting or hindering self-management behaviour of patients.^{63,64} Secondly, researchers could investigate specifically why health-care providers appear to find it difficult to adhere to best-practice guidelines for diagnosis and treatment of COPD.^{65,66} For example, in one recent UK-based study, unwarranted prognostic pessimism among intensive care physicians was found to be associated with some COPD patients being denied admission to intensive care,⁶⁷ a sobering finding with very grave consequences for patients. Thirdly, researchers may investigate the cultural forces that lead COPD to be perceived as less ‘sexy’ an illness in the minds of the public at large, compared to say breast cancer or myocardial infarction.⁶⁸ Such disproportionality in public regard has implications for how public funds are used in health-care and for how patients are treated by others in society. Patient organizations may be instrumental agents in improving the public image of COPD, thereby helping patient and their partners to feel less stigmatized and more comfortable in managing COPD in daily life.

The clinical implications of our findings may be put into the context of the evolution of traditional patient education into self-management-based intervention.⁵ The contrast between these two approaches essentially reduces to four questions, each of which carries practical implications for patients, physicians, and society⁶ [p. 2471]: (a) what is “taught” in the intervention? (information and technical skills [patient education]; or skills for acting on problems [self-management]) (b) How are problems formulated? (As reflecting inadequate disease control; or as identified by the patient based on his/her experiences and as may or may not be related to the disease) (c) How does the “education” relate to the disease? (By being disease-specific and teaching information and technical skills; or by providing problem-solving skills that are relevant to the consequences of chronic conditions in general), and (d) who is the most appropriate educator? (A health-care professional; or peer leaders and/or other patients, with or without a health-care provider, often in group settings).

This evolution will require change in medical curricula,⁶⁹ more attention on self-management in relevant guidelines,⁷ and encouragement of patients and patient organizations to develop and revise such guidelines. In addition, a move to self-management programmes raises the need to evaluate such programmes more precisely, so that we know more about which patient will benefit most on which outcome measure by using which self-management skill(s). In our experience, psychological expertise has not always been welcome in health-care settings. Some 30 years ago one of us overheard a hospital director stating that he “would rather have the plague in this hospital than psychologists”. Such attitudes seem to reflect the past, and are certainly “a road to ruin”, given the accumulated knowledge on the optimization of interventions based on empirical studies in which

psychologists have been key collaborators with respiratory physicians and other health-care providers. The increasing sophistication of research and intervention approaches in this area, together with an emphasis both on empirical evidence and on patient-centeredness, suggests that the future will bring further benefits to all concerned. Thus, we have good reason to look forward to the next 50 years of behavioural research on patients with COPD, during which the field can leave the road to ruin far behind, and aspire instead to head towards something of a “highway to heaven”. To paraphrase a recent editorial in *The Lancet*,⁷⁰ with the right medical care, it is reasonable to aspire to informing and empowering COPD patients so that they can fully control their condition and live normal active lives. The refinement of psychological research efforts will be central to this endeavor.

Conflict of interest

None of the authors have a conflict of interest to declare in relation to this work.

Acknowledgement

The writing of this paper was facilitated by research grants from the Netherlands Asthma Foundation (project numbers 78.22, 83.22, 85.07, 88.54, 90.37, 92.31, 98.15, 03.80 and 06.07), and by the Society for Research on Psychosocial Stress (SOPS). Jan Schoones, librarian at the Walaeus Library LUMC, helped with defining the literature search.

References

1. Rather LJ. Rudolph Virchow and scientific medicine. *Arch Intern Med* 1957;100:1007–14.
2. Gudmundsson G, Gislason T, Janson C, Lindberg E, Ulrik CS, Brøndum E, et al. Depression, anxiety and health status after hospitalisation for COPD: a multicentre study in the Nordic countries. *Respir Med* 2006;100:87–93.
3. Hill K, Geist R, Goldstein RS, Lacasse Y. Anxiety and depression in end-stage COPD. *Eur Respir J* 2008;31:667–77.
4. Rabe KF, Beghé B, Luppi F, Fabbri LM. Update in chronic obstructive pulmonary disease 2006. *Am J Respir Crit Care Med* 2007;175:1222–32.
5. Niesink A, Trappenburg JCA, de Weert-van Oene GH, Lammers JWJ, Verheij TJM, Schrijvers AJP. Systematic review of the effects of chronic disease management on quality-of-life in people with chronic obstructive pulmonary disease. *Respir Med* 2007;101:2233–9.
6. Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. *JAMA* 2002;288:2469–75.
7. Global strategy for the diagnosis, management and prevention of COPD, global initiative for chronic obstructive lung disease (GOLD) Available from: <http://www.goldcopd.org>; 2007.
8. Gallefoss F, Bakke PS. Cost-benefit and cost-effectiveness analysis of self-management in patients with COPD – a 1-year follow-up randomized, controlled trial. *Respir Med* 2002;96:424–31.
9. Voll-Aanerud M, Eagan TML, Wentzel-Larsen T, Gulsvik A, Bakke PS. Respiratory symptoms, COPD severity, and health related quality of life in a general population sample. *Respir Med* 2008;102:399–406.
10. Diamant Z, Boot JD, Virchow JC. Summing up 100 years of asthma. *Respir Med* 2007;101:378–88.
11. Cazzola M, Donner CF, Hanania NA. One hundred years of chronic obstructive pulmonary disease (COPD). *Respir Med* 2007;101:1049–65.
12. Wildiers H, Kunkler I, Biganzoli L, Fracheboud J, Vlastos G, Bernard-Marty C, et al. Management of breast cancer in elderly individuals: recommendations of the International Society of Geriatric Oncology. *Lancet Oncol* 2007;8:1101–15.
13. Guideline Development Group. Management of diabetes from preconception to the postnatal period: a summary of NICE guidance. *Br Med J* 2008;336:714–7.
14. Kiley JP, Nabel EG. Treating COPD. *N Engl J Med* 2007;356:867.
15. Kaptein AA, Creer TL, editors. *Respiratory disorders and behavioral medicine*. London: Martin Dunitz; 2002.
16. Kaptein AA, Scharloo M, Fischer MJ, Snoei L, Weinman J. Chronic obstructive pulmonary disease (COPD). In: Newman S, Mulligan K, Steed L, editors. *Chronic physical illness: self-management and behavioural interventions*. London: Routledge; 2008. p. 254–70.
17. Clouser SB, Ganz PA, Lipscomb J, Reeve BB. Patient-reported outcomes assessment in cancer trials. *J Clin Oncol* 2007;25:5049–50.
18. Thong SYM, Kaptein AA, Benyamini Y, Krediet RT, Boeschoten EW, Dekker FW. Association between a self-rated health question and mortality in young and old dialysis patients: a cohort study. *Am J Kidney Dis* 2008;52:111–7.
19. French TM, Alexander F. Psychogenic factors in bronchial asthma. *Psychosom Med Monogr* 1941;4:82–101.
20. Goldstein AP. *Psychotherapeutic attraction*. New York: Pergamon Press; 1971.
21. Rosser R, Denford J, Heslop A, Kinston W, Macklin D, Minty K, et al. Breathlessness and psychiatric morbidity in chronic bronchitis and emphysema: a study of psychotherapeutic management. *Psychol Med* 1983;13:93–110.
22. Webb MW, Lawton AH. Basic personality traits characteristic of patients with primary obstructive pulmonary emphysema. *J Am Geriatr Soc* 1961;9:590–610.
23. Agle DP, Baum GL. Psychological aspects of chronic obstructive pulmonary disease. *Med Clin North Am* 1977;61:749–58.
24. Hynninen KMJ, Breivte MH, Wiborg AB, Pallesen S, Nordhus IH. Psychological characteristics of patients with chronic obstructive pulmonary disease: a review. *J Psychosom Res* 2005;59:429–43.
25. Prigatano GP, Parsons O, Wright E, Levin DC, Hawryluk G. Neuropsychological test performance in mildly hypoxemic patients with chronic obstructive pulmonary disease. *J Consult Clin Psychol* 1983;51:108–16.
26. Grant I, Prigatano GP, Heaton RK, McSweeney AJ, Wright EC, Adams KM. Progressive neuropsychologic impairment and hypoxemia. Relationship in chronic obstructive pulmonary disease. *Arch Gen Psychiatry* 1987;44:999–1006.
27. Crews WD, Jefferson AL, Bolduc T. Neuropsychological dysfunction in patients suffering from end-stage chronic obstructive pulmonary disease. *Arch Clin Neuropsychol* 2001;16:643–52.
28. Zieliński J. Effects of long-term oxygen therapy in patients with chronic obstructive pulmonary disease. *Curr Opin Pulm Med* 1999;5:81–7.
29. Stewart BN, Hood CI, Block AJ. Long-term results of continuous oxygen therapy at sea level. *Chest* 1975;68:486–92.
30. Block AJ, Castle JR, Keitt AS. Chronic oxygen therapy. Treatment of chronic obstructive pulmonary disease at sea level. *Chest* 1974;65:279–88.
31. Jones PW, Quirk FH, Baveystock CM. The St. George’s respiratory questionnaire. *Respir Med* 1991;85(Suppl. B):25–31.
32. Guyatt GH, Berman LB, Townsend M, Pugsley SO, Chambers LW. A measure of quality of life for clinical trials in chronic lung disease. *Thorax* 1987;42:773–8.

33. Schmier JK, Halpern MT, Higashi MK, Bakst A. The quality of life impact of acute exacerbations of chronic bronchitis (AECB): a literature review. *Qual Life Res* 2005;14:329–47.
34. Crockett AJ, Cranston JM, Moss JR, Alpers JH. The MOS SF-36 health survey questionnaire in severe chronic airflow limitation: comparison with the Nottingham Health Profile. *Qual Life Res* 1996;5:330–8.
35. Domingo-Salvany A, Lamarca R, Ferrer M, Garcia-Aymerich J, Alonso J, Félez M, et al. Health-related quality of life and mortality in male patients with chronic obstructive pulmonary disease. *Am J Respir Crit Care Med* 2002;166:680–5.
36. Kinsman RA, Yaroush RA, Fernandez E, Dirks JF, Schocket M, Fukuhara J. Symptoms and experiences in chronic bronchitis and emphysema. *Chest* 1983;83:755–61.
37. Kinsman RA, Dirks JF, Jones NF. Psychomaintenance of chronic physical illness. In: Millon C, Green R, Meagher R, editors. *Handbook of clinical health psychology*. New York: Plenum Press; 1982. p. 435–66.
38. Neff TA, Petty TL. Outpatient care for patients with chronic airway obstruction – emphysema and bronchitis. *Chest* 1971;60:115–7S.
39. Blackstock F, Webster KE. Disease-specific health education for COPD: a systematic review of changes in health outcomes. *Health Educ Res* 2007;22:703–17.
40. Lazarus RS, Folkman S. *Stress, appraisal and coping*. New York: Springer; 1984.
41. Scharloo M, Kaptein AA, Weinman JA, Willems LNA, Rooijmans HGM. Physical and psychological correlates of functioning in patients with chronic obstructive pulmonary disease. *J Asthma* 2000;37:17–29.
42. Leventhal H, Brissette I, Leventhal E. The common-sense model of self-regulation of health and illness. In: Cameron LD, Leventhal H, editors. *The self-regulation of health and illness behaviour*. London: Routledge; 2003. p. 42–65.
43. Scharloo M, Kaptein AA, Schlosser M, Pouwels H, Bel EH, Rabe KF, et al. Illness perceptions and quality of life in patients with chronic obstructive pulmonary disease. *J Asthma* 2007;44:575–81.
44. Kaptein AA, Scharloo M, Fischer MJ, Snoei L, Cameron L, Sont JK, et al. Illness perceptions and COPD: an emerging field for COPD patient management. *Respir Med* in press.
45. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. *Patient Educ Couns* 2002;48:177–87.
46. Bourbeau J. Disease-specific self-management programs in patients with advanced chronic obstructive pulmonary disease. A comprehensive and critical evaluation. *Dis Manag Health Outcomes* 2003;11:311–9.
47. Howland J, Nelson EC, Barlow PB, McHugo G, Meier FA, Brent P, et al. Chronic obstructive airway disease. Impact of health education. *Chest* 1986;90:233–8.
48. von Korff M, Gruman J, Schaefer J, Curry SJ. Collaborative management of chronic illness. *Ann Intern Med* 1997;127:1097–102.
49. Gadoury M-A, Schwartzman K, Rouleau M, Maltais F, Julien M, Beupré A, et al. Self-management reduces both short- and long-term hospitalisation in COPD. *Eur Respir J* 2005;26:853–7.
50. Gallefoss F. The effects of patient education in COPD in a 1-year follow-up randomized, controlled trial. *Patient Educ Couns* 2004;52:259–66.
51. Effing T, Monnikhof E, van der Valk P, van der Palen J, van Herwaarden C, Partridge M, et al. Self-management education for patients with chronic obstructive pulmonary disease. *Cochrane Database Syst Rev* 2007 Oct 17;(4): CD002990.
52. Petrie KJ, Cameron LD, Ellis CJ, Buick D, Weinman J. Changing illness perceptions after myocardial infarction: an early intervention randomized controlled trial. *Psychosom Med* 2002;64:580–6.
53. Atkins CJ, Kaplan RM, Timms RM, Reinsch S, Lofback K. Behavioral exercise programs in the management of chronic obstructive pulmonary disease. *J Consult Clin Psychol* 1984;52:591–603.
54. Troosters T, Casaburi ER, Gosselink R, Decramer M. Pulmonary rehabilitation in chronic obstructive pulmonary disease. *Am J Respir Crit Care Med* 2005;172:19–38.
55. Lacasse R, Goldstein R, Lasserion TJ, Martin S. Pulmonary rehabilitation for chronic obstructive pulmonary disease. *Cochrane Database Syst Rev* 2006;(4): CD003793.
56. Fischer MJ, Scharloo M, Abbink JJ, Thijs-van Nies A, Rudolphus A, Snoei L, et al. Participation and drop-out in pulmonary rehabilitation: a qualitative analysis of the patient's perspective. *Clin Rehabil* 2007;21:212–21.
57. Kaptein AA, van Klink RCJ, de Kok F, Scharloo M, Snoei L, Broadbent E, et al. Sexuality in patients with asthma and COPD. *Respir Med* 2008;102:198–204.
58. Adams SG, Smith PK, Allan PF, Anzueto A, Pugh J, Cornell JE. Systematic review of the chronic care model in chronic obstructive pulmonary disease prevention and management. *Arch Intern Med* 2007;167:551–61.
59. Newman S, Steed L, Mulligan K. Self-management interventions for chronic illness. *Lancet* 2004;364:1523–37.
60. Arendt H. *The human condition*. Chicago: University of Chicago Press; 1958.
61. Cassell EJ. *The nature of suffering and the goals of medicine*. 2nd ed. Oxford: Oxford University Press; 2004.
62. Gross CP, Anderson GF, Powe NR. The relation between funding by the national institutes of health and the burden of disease. *N Engl J Med* 1999;340:1881–7.
63. Ashmore JA, Emery CF, Hauck ER, MacIntyre NR. Marital adjustment among patients with chronic obstructive pulmonary disease who are participating in pulmonary rehabilitation. *Heart Lung* 2005;34:270–8.
64. Seamark DA, Blake SD, Seamark CJ, Halpin DMG. Living with severe chronic obstructive pulmonary disease (COPD): perceptions of patients and their careers. *Palliat Med* 2004;18:619–25.
65. Barr RG, Celli BR, Martinez FJ, Ries AL, Rennard SI, Reilly JJ, et al. Physician and patient perceptions in COPD: the COPD resource network needs assessment survey. *Am J Med* 2005;118:e9–17.
66. Smith BJ, Dalziel K, McElroy HJ, Ruffin RE, Frith PA, McCaul KA, et al. Barriers to success for an evidence-based guideline for chronic obstructive pulmonary disease. *Chron Respir Dis* 2005;2:121–31.
67. Wildman MJ, Sanderson C, Groves J, Reeves BC, Ayres J, Harrison D, et al. Implications of prognostic pessimism in patients with chronic obstructive pulmonary disease (COPD) or asthma admitted to intensive care in the UK within the COPD and asthma outcome study (CAOS): multicentre observational cohort study. *Br Med J* 2007;335:1132–4.
68. Viney LL. *Images of illness*. 2nd ed. Malabar, FL: Robert E. Krieger Publishing Co.; 1989.
69. Holman H. Chronic disease – the need for a new clinical education. *JAMA* 2004;292:1057–9.
70. Editorial. New guidelines for better asthma control. *Lancet* 2007;370:802.