



chronic respiratory illness

Simon J. Williams

**Also available as a printed book
see title verso for ISBN details**

Chronic respiratory illness

Chronic obstructive airways disease (COAD: bronchitis, emphysema and chronic asthma) is a major medical, psychological, social and economic problem. Breathlessness is one of the most distressing and disabling symptoms of COAD, and it has long been apparent that the condition results in impaired quality of life.

Drawing upon sociological and psychological sources, and his own detailed research within this area, Simon Williams sensitively portrays the meaning, experience and impact of COAD. Sufferers' and their families' own accounts are used to portray the various stages and aspects of COAD, ranging from the experience of symptoms and the management of medical regimens, to the practical problems it creates in daily life and the more diffuse and intangible ways in which it impinges upon social and family life. He also provides a comprehensive review of the relevant psychosocial literature and concludes by discussing some of the policy implications for health care professionals.

Chronic Respiratory Illness will be of immense value to health professionals and others who care for sufferers and their families. It will also be of interest to students and researchers working in medical sociology, health psychology, medicine and nursing.

Simon J. Williams is Lecturer in Sociology at the University of Warwick.

The Experience of Illness

Series Editors: Ray Fitzpatrick and Stanton Newman

Other titles in the series

Diabetes

David Kelleher

Multiple Sclerosis

Ian Robinson

Back Pain

Michael Humphrey

Epilepsy

Graham Scambler

Breast Cancer

Lesley Fallowfield with Andrew Clark

Colitis

Michael Kelly

Menstrual Disorders

Annette Scambler and Graham Scambler

Chronic respiratory illness

Simon J. Williams



London and New York

First published 1993
by Routledge
11 New Fetter Lane, London EC4P 4EE

This edition published in the Taylor & Francis e-Library, 2005.

“To purchase your own copy of this or any of Taylor & Francis or Routledge’s collection of thousands of eBooks please go to www.eBookstore.tandf.co.uk.”

Simultaneously published in the USA and Canada
by Routledge
29 West 35th Street, New York, NY 10001

© 1993 Simon J. Williams

All rights reserved. No part of this book may be reprinted or reproduced or utilized in any form or by any electronic, mechanical, or other means, now known or hereafter invented, including photocopying and recording, or in any information storage or retrieval system, without permission in writing from the publishers.

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library.

Library of Congress Cataloging in Publication Data
Williams, Simon (Simon Johnson), 1961– Chronic respiratory illness/Simon Williams. p. cm.—(The Experience of illness) Includes bibliographical references and index. 1. Lungs—Diseases, Obstructive—Psychological aspects. 2. Lungs—Diseases, Obstructive—Social aspects. I. Title. II. Series. RC776.03W55 1993 92–39592 362.1'962–dc20 CIP

ISBN 0-203-39256-6 Master e-book ISBN

ISBN 0-203-39537-9 (Adobe eReader Format)
ISBN 0-415-07657-9 (Print Edition)

Contents

Editors' preface	vi
Author's preface	vii
1 Chronic obstructive airways disease: clinical nature and epidemiology	1
2 The subjective experience and management of symptoms	7
3 Medical care	29
4 Practical problems of daily life	51
5 Problems of work and income	73
6 Social and family life	93
7 Conclusions and policy implications	121
References	125
Name index	131
Subject index	133

Editors' preface

Chronic respiratory disorders are a major source of distress and disability for sufferers and their families. They are among the large class of human illnesses in which the relationship between underlying physiological indices and symptomatic severity is only weak. This is *prima-facie* evidence that personal meaning and social context have a major influence on the experience of respiratory problems. As Simon Williams points out, breathing is a fundamental function that we take for granted; when it is disturbed, for whatever reason, it may constitute the most distressing of experiences.

Simon Williams has provided us with a unique account of the lives of individuals who experience respiratory problems. His study is based on detailed investigation of a sample of sufferers' experiences using both standardised quantitative measures of impairment, disability and handicap, as well as in-depth interviews. The result is a remarkably well-observed and sensitive analysis of respiratory disorders as viewed by sufferers. It is vital to be reminded of the scope for improving individuals' quality of life. The author makes a powerful case for those who would see important challenges surrounding the task of improving the daily lives of people with chronic illnesses. The first stage of this task is to be fully aware of the true impact of illness. Work such as this book is central in displaying graphically the burden of illness which sufferers, carers, families and health services confront.

Ray Fitzpatrick and Stanton Newman, 1993

Author's preface

The main source upon which this book draws is a detailed study, by the author, of the consequences of chronic respiratory illness (Chronic Obstructive Airways Disease—COAD), focusing particularly on the meaning, experience, impact (i.e. physical, psychological, social, economic and material) and management of the condition. This involved both a detailed and systematic *quantitative* investigation of these issues with a sample of ninety-two COAD out-patients, and further in-depth, *qualitative*, tape-recorded, domiciliary interviews with a smaller sub-sample of twenty-four sufferers and, wherever possible, their carers. It is the latter, qualitative data source upon which this book principally relies for insights into the meaning, experience, impact and management of COAD, for both sufferers and their families. Further details of the study are to be found in Williams (1990), and Williams and Bury (1989a, b).

It should be emphasised at the outset that this is *not* primarily a book about the experience of asthma, the study of which represents a separate, yet related, issue. Rather, as [Chapter one](#) explains, the population of COAD sufferers tends to be predominantly composed of those with chronic obstructive bronchitis and emphysema. Only those cases of chronic asthma where the obstruction has, over a period of time usually spanning many years, become less *reversible* may be subsumed under this rubric.

I would like to thank Mike Bury, my Ph.D. supervisor, for his help, encouragement, guidance and support over the years; Mike Calnan and everyone else at the Centre for Health Services Studies, University of Kent, who have made the time I spent writing this book so enjoyable; the editors, Ray Fitzpatrick and Stanton Newman, for offering me the chance to write a book for the series, and to Ray in particular for his general support and encouragement over the years; Dr Robin Rudd and his colleagues for help in actually setting up the study and allowing me access to their patients; and also, of course, the patients themselves and their families, who gave of their time so generously despite the stress and strains they, undoubtedly, were under. Needless to say, the names of all individuals referred to within the book have been changed in order to preserve confidentiality.

Thanks also go to Gill Bendelow, Sarah Cant, Alicia Deale and Pete and Fran Cuthbert, for help, encouragement and support. Last, but certainly not least, thanks

must also go to my parents, to whom I undoubtedly owe the greatest debt of all. This book is dedicated to them both.

Chapter 1

Chronic obstructive airways disease

Clinical nature and epidemiology

Chronic obstructive airways disease (COAD: emphysema, chronic obstructive bronchitis and chronic asthma) is a 'debilitating disease of adult life'. Despite differences of opinion amongst pulmonary physicians as to the precise definition of COAD, the term has nevertheless enjoyed common usage within the medical literature for approximately twenty-five years and most would agree that the cardinal feature is one of expiratory obstruction to airflow (McSweeny and Labuhn 1990).

COAD is a major, though neglected, medical and social problem in the United Kingdom today. Indeed, it is one of the leading causes of absence from work in the UK (OHE 1977), and it has long been apparent that COAD results in impaired quality of life. As Capel and Caplin state, COAD 'maims before it kills' (1964:16). Dyspnoea (breathlessness) is one of the most distressing (Hinton 1967) and disabling (Lane 1988) symptoms of COAD. As Hinton notes: 'The breathlessness experienced by those with slowly encroaching disease of the lungs is not easily relieved' (1967:80). Indeed, the ability to breathe is the *sine qua non* of life. Consequently, 'an elemental fear is soon aroused' (Hinton 1967). Although the mechanisms of breathlessness are poorly understood, there is a growing body of evidence to suggest that psychosocial factors are implicated, even when severe lung disease is present (Rosser and Guz 1981, Jones 1988). Furthermore, the fact that COAD in the UK disproportionately affects those from working-class backgrounds (Townsend *et al.* 1988), who may well be least able to cope with its consequences (i.e. the fact that it is 'socially patterned': MacIntyre 1986, 1988), adds a further dimension of disadvantage to both sufferers and their families.

THE CLINICAL NATURE OF COAD

In 1808 Charles Badham adopted the term 'bronchitis' to define collectively 'chronic pectoral (chest) complaints, especially those of people advanced in life' (OHE 1977). However, through an intriguing history of shifting terminology and conceptual acrobatics (Scadding 1981), we have now arrived at the term *chronic obstructive airways disease* (COAD)—or something similar such as *chronic obstructive pulmonary disease* (COPD), or *chronic airflow limitation* (CAL).

COAD is a rather broad catch-all term which encompasses chronic obstructive bronchitis, emphysema and, although there does not seem to be any consensus here, certain cases of chronic asthma, in recognition of the fact that these conditions often co-exist.

The Medical Research Council Committee on the Aetiology of Chronic Bronchitis considered the issue of terminology in 1965. They accepted that the criteria for emphysema should be defined in morbid-anatomical terms. They suggested that the term 'chronic bronchitis', which was by now firmly entrenched in British clinical usage, should be retained with formal definitions, primarily in clinical-descriptive terms (Scadding 1981). Thus, chronic bronchitis may be defined as the 'occurrence of cough and phlegm on most days for at least three months in the year for two successive years' (MRC 1965:775). Chronic bronchitis is often complicated by recurrent chest illness and may be associated with airflow obstruction leading to breathlessness on exertion, in which case it is referred to as chronic *obstructive* bronchitis. Emphysema often co-exists.

Emphysema may be said to be present where there is 'enlargement of airspaces beyond the terminal non-respiratory bronchioles, usually with destruction of lung tissue' (RCP 1981). These changes, which are usually caused by very fine penetrations of smoke, dust or other substances of a noxious nature, lead to a loss of the lungs' natural elasticity (recoil) which results in the lungs tending to be permanently inflated. As the Royal College of Physicians' (RCP) report points out:

The diagnosis covers a range of types of abnormality which can only be identified with certainty by pathological examination. The main symptom is breathlessness on exertion and this is associated with changes in lung function which may take a characteristic form. However, where chronic bronchitis co-exists it is seldom possible to separate their respective contributions to respiratory disability.

(1981:70)

Finally, asthma is characterised, in contrast to chronic obstructive bronchitis and emphysema, by 'obstruction to airflow which is *variable* spontaneously and in response to treatment. However, over a period of time, which is usually measured in years, the obstruction may become less reversible' (RCP 1981:70). Thus, whilst the majority of asthma sufferers are not included under the rubric of COAD, those chronic asthmatics whose airflow obstruction has, over time, become less reversible may be subsumed under this general term.

Hence the term COAD refers to those respiratory conditions characterised by abnormally high resistance to airflow in intrapulmonary airways. This may be due to changes of various sorts in the airways themselves or to emphysema, or to a combination of these. Consequently, the term 'airflow obstruction' has been used rather widely and loosely to refer to this abnormality of function (Scadding 1981). This is usually diagnosed when the degree of fixed obstruction results in a 'Forced

Expiratory Volume in one second (FEV_1) less than 70 per cent of predicted values' for age, sex and height (Guyatt *et al.* 1987). Thus defined, the population of COAD sufferers tends to be predominantly composed of those with chronic obstructive bronchitis and emphysema, together with a small proportion of chronic asthma suffers whose obstruction has become progressively less reversible over time.

As mentioned above, the predominant and most distressing symptom is that of breathlessness on exertion (dyspnoea), which is frequently accompanied by a chronic cough and excessive mucus production. In addition, in certain more advanced cases, oxygen deficiencies (hypoxaemia) and/or excessive carbon dioxide retention (hypercapnia) in the blood (i.e. blood gas abnormalities) are to be found—which may result in neuro-psychological dysfunction (Prigatano and Grant 1988)—together with decreased cardiac efficiency and right-sided heart failure (cor pulmonale). Consequently, eventual death results.

It is not within the scope of this chapter to go into existing research on possible causal factors in the aetiology of such conditions. However, suffice it to say that the contribution of factors such as the following: cigarette smoking (Fletcher *et al.* 1976)—itself class-linked (Blaxter 1987, 1990); air pollution (Colley *et al.* 1970, 1973); occupation (Hunter 1975); housing and material conditions (Holma and Kjaer 1980, Burr *et al.* 1981); and early childhood experience (Kiernan *et al.* 1976, Britten *et al.* 1987), is now well established. In addition certain hereditary genetic factors appear to modify susceptibility—the key one being an α_1 -antitrypsin deficiency. However, of all these factors, Petty (1985) has suggested that COAD would be a relatively minor health problem if people did not smoke.

Despite considerable uncertainty concerning the early natural history of COAD, it is now widely accepted that it begins at a relatively early stage in life and is characterised by a slowly progressive, insidious, deterioration of lung function for many years prior to the development and presentation of frank clinical illness (Burrows 1985). The perception of COAD on the patient's part is, of course, subject to various social and cultural determinants, such that onset rarely coincides with the subjective perception and presentation of symptoms. However, it remains possible that COAD can have a fairly abrupt onset, with a rapid decrease in ventilatory capacity occurring during the few years prior to the onset of symptoms (Burrows 1985).

The subsequent course of the disease following the development of significant symptomatology is considerably better documented and understood. As Burrows notes:

In general patients become unable to perform very vigorous exertion once their FEV_1 falls much below 1.5 litres, but are often able to continue work, unless their job is very physically demanding, until their FEV_1 falls below 1.0 litres. However, there is considerable variability in the relationship of impairment to disability, some of which appears to relate to psychological factors.

(1985:37)

The degree of disability accompanying COAD may usefully be classified according to the following five levels of functioning:

- 1 Patient with recognised disease but with *no* restriction: is able to do what peers can do and continues usual life style.
 - 2 Patient with *minimally* restricted activity who is able to do productive work: has some difficulty keeping up with peers and has begun to modify life style.
 - 3 Patient with *moderately* restricted activity: is not homebound but may not be able to do productive work, however still able to care for him/herself.
 - 4 Patient with *markedly* restricted activity: limited outdoor mobility, unable to do productive work but is still able to care for him/herself, albeit with difficulty.
 - 5 Patient with *very severely* restricted activity: is essentially/totally housebound, needs help with personal care/is unable to care for him/herself.
- (Adapted from the American Lung Association 1975.)

Concerning longevity, Burrows finds that ‘median survival is approximately 10 years when the FEV₁ is 1.4 litres, approaches 4 years when FEV₁ has fallen to 1.0 litres and is little more than 2 years when the FEV₁ nears 500 millilitres’ (1985:37–8). The medical treatment and management of COAD is discussed in [Chapter three](#).

THE EPIDEMIOLOGY OF COAD

Bronchitis, emphysema and asthma, amongst other respiratory conditions, are major contributors to the national pool of chronic illness and disability in the United Kingdom. International comparisons of mortality rates from such conditions indicate quite clearly that they affect the UK populace to a far greater extent than any other country in the world (OHE 1977). As the Office of Health Economics (OHE) report states: ‘Mortality in the UK from all chronic lung conditions during the mid 1960’s was probably in the order of 10 times that experienced in Japan, Sweden and Norway and several times that which occurred in most other industrialised countries’ (1977:18). In the United States of America, the prevalence rate in 1980 was 4.75 per cent, and COAD accounted for approximately 2.5 per cent of all deaths—thus ranking as the fifth leading cause of mortality (Tockman *et al.* 1985). However, at least some of these international differences could partly be explained by the different usage of terminology (e.g. the difference between the frequently used clinical diagnosis of emphysema in the United States and the predominantly pathological diagnosis adopted in the United Kingdom at autopsy). Furthermore, as mentioned earlier, mortality rates for diseases of the respiratory system, such as bronchitis, show extremely steep social class gradients which have been in existence throughout the twentieth century.

Whilst concerning morbidity, a survey of 92 GPs distributed throughout the country found that the percentage of men and women between the ages of 40 and 60 who were suffering from chronic bronchitis rose sharply with descending social class from 6 per cent in class I to 26 per cent in class V (Townsend *et al.* 1988).

A useful source of data is to be found in the Royal College of Physicians' (RCP) report on disabling chest disease (1981). According to the report, in 1976/7 the number of person-days lost from work due to bronchitis, chronic bronchitis and emphysema was in the order of 26 million for men and 2.6 million for women; constituting approximately 10 per cent of all recorded working days lost due to sickness absence. The cost of sickness benefit, if expressed at current rates, was somewhat in excess of 100 million, and the total economic cost to the community considerably more. As the RCP report states: 'The associated load on the GP service was reflected in the GP consultations of which, in 1971, 21 per cent were on account of respiratory ill-health including infections of the upper and lower respiratory tracts' (1981:71).

The numbers suffering from chronic respiratory illness and disability are also reflected in the figures for invalidity benefit and for those who are in receipt of non-contributory invalidity pension. In 1977, approximately 68,000 men of working age and 6,000 women were in receipt of these benefits as a result of chronic respiratory illness, whilst in 1978 the Disabled Persons' Register, admittedly a poor measure of disability in the community, included some 57,000 entries as a result of respiratory disability (RCP 1981). As the RCP report states:

if it assumed that the number of chronically sick constitute a similar proportion of the national pool of such persons then the total number of men of working age with respiratory impairment sufficient to make them potential candidates for invalidity benefit is of the order of 0.3 million.

(1981:71)

This figure is consistent with certain epidemiological evidence concerning the prevalence of chronic bronchitis in the community (e.g. 25 per cent amongst men aged 50–9 years: Fletcher *et al.* 1976).

However, disability, of course, varies considerably in terms of its degree of severity. Thus in Harris *et al.*'s survey of the 'handicapped and impaired in Great Britain' (1971), the actual number of individuals with a respiratory disorder who required help with some item of daily living was estimated to be about 20,000. Above working age about twice this number were found to be similarly disabled (Harris *et al.* 1971). A further indication of severe disability can be found in the figures for attendance and mobility allowances. As the RCP report states:

at the end of 1978 there were 7,600 persons with chronic respiratory disease on whose behalf an attendance allowance was being paid; 6,000 being cases of bronchitis. In October 1979 mobility allowance was being paid to some 4,209 persons aged 60 years or less disabled by chronic lung disease.

(1981:71)

A more recent estimate by the Office of Population Censuses and Surveys (OPCS 1988a), suggests that of the just over 6 million disabled adults living in Great Britain today, 13 per cent of those living in private households and 6 per cent of those living in communal establishments suffer from diseases of the respiratory system.

The figures for previous years indicate that the number of persons receiving sickness benefit or invalidity benefit for bronchitis has remained relatively stable. In contrast, the number of hospital admissions on account of chronic bronchitis and emphysema has been steadily declining, as has the associated mortality rate, which rises with age (RCP 1981). However, mortality rates attributable to such conditions convey a somewhat distorted picture as the condition is rarely fatal in middle life; around four-fifths of all deaths occurring in people aged 65 or over. Hence death from the condition usually occurs only after years of progressively worsening disability and suffering (OHE 1977). On average, approximately 10 per cent of hospital beds throughout the year are occupied by chest cases, of whom about half are chronic bronchitics, with the proportion rising steeply in the winter months (RCP 1981). The picture is generally similar for men and women, although fewer women are affected. The cost to the NHS of treating such conditions is enormous; estimates indicate that in 1974, for example, the treatment of bronchitis and emphysema cost the NHS approximately 95 million (OHE 1977). As the RCP report (1981) notes, for a variety of reasons, ranging from problems surrounding actual clinical diagnosis to the measurement of disability, the above figures are inevitably of limited reliability and validity. However, the biasing factors do not all operate in a similar direction and so, when taken together, they confirm that the extent of respiratory disablement, and the management and support of those suffering such conditions, present us with major problems both in terms of human suffering and misery, and in terms of the demands placed upon health and welfare services and the community as a whole.

Having sketched a brief clinical and epidemiological picture of COAD, it is to a more detailed discussion of the *experiential* and *subjective* dimensions of its symptomatology that the next chapter now turns.