Long-Term Conditions

NURSING CARE AND MANAGEMENT

Edited by Liz Meerabeau & Kerri Wright

WILEY-BLACKWELL

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Contents

‘We can envision in chronic illness and its therapy a symbolic bridge that connects the body, self and society. This network interconnects physiological processes, meanings and relationships so that our social word is linked recursively to our inner experience. Here we are privileged to discover powers within and between us that can either amplify suffering or disability or dampen symptoms and therefore contribute to care.’

Arthur Kleinman (1988:xiii)
The Illness Narratives – Suffering, Healing and the Human Condition
Basic Books, New York

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WILEY-BLACKWELL
A John Wiley & Sons, Ltd., Publication

This edition first published 2011 © 2011 by Blackwell Publishing Ltd

Blackwell Publishing was acquired by John Wiley & Sons in February 2007. Blackwell's publishing program has been merged with Wiley's global Scientific, Technical and Medical business to form Wiley-Blackwell.

Registered office: John Wiley & Sons, Ltd, The Atrium, Southern Gate, Chichester, West Sussex, PO19 8SQ, UK

Editorial offices: 9600 Garsington Road, Oxford, OX4 2DQ, UK
The Atrium, Southern Gate, Chichester, West Sussex, PO19 8SQ, UK
2121 State Avenue, Ames, Iowa 50014-8300, USA

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Library of Congress Cataloging-in-Publication Data
Long-term conditions : nursing care and management/edited by Liz Meerabeau and Kerri Wright.
p. ; cm.
Includes bibliographical references and index.
ISBN 978-1-4051-8338-3 (pbk. : alk. paper)
1. Chronic diseases–Nursing. 2. Long-term care of the sick. I. Wright, Kerri. II. Meerabeau, Liz.
[DNLM: 1. Chronic Disease–economics. 2. Chronic Disease–therapy. 3. Health Care Costs. 4. Health Policy. 5. Patient Education as Topic. 6. Self Care. WT 500]
RT120.C45L66 2011
616′.044–dc22
2010049567

A catalogue record for this book is available from the British Library.

This book is published in the following electronic formats: ePDF 9781444341003; Wiley Online Library 9781444341034; ePub 9781444341010

Foreword

This is a very important book. Although there have always been people with long-term conditions (LTCs) on nurses' caseloads, it is only in recent years that we have recognised the breadth and depth of these individuals' needs, and understood how much further we could go to meet them. For too many years, health professionals saw their interactions with people with LTCs as episodic, repetitive and unrewarding.

A better understanding of the nature and impact of these conditions on individuals has changed both attitudes and practice. We are more focused on prevention, both primary and secondary, for diseases once accepted as unavoidable. We are more proactive in finding people with LTCs, and instituting management to reduce their impact. And, most importantly, we now recognise that people with these conditions know a great deal about them, and are usually able and willing to take much more control than we had ever guessed. The advent of portable assistive technology, which can be used at home with minimal training, has helped enormously to shift the knowledge and power in disease management from the professional to the patient.

The timing of these changes is important. The number of people with LTCs in the United Kingdom and worldwide is set to grow exponentially. Lifestyle factors, including obesity and inappropriate diet, environmental challenges as well as some unknown causes, are all leading to sharp rises in conditions such as diabetes, asthma and heart disease. In a world with rising health care demand but caps on health care spending, managing LTCs well is a professional imperative for the sake of the individual patient and the wider health system.

This book is a very welcome tool, which will enable health professionals to understand the complexity, challenge and rewards of proactively managing LTCs. Putting this knowledge into skilled practice, in partnership with patients, will transform the lives of many individuals and their families, and thus fulfil the fundamental purpose of nursing.

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Acknowledgements

Thanks to Rona Dury, Theresa Massey, Alice Neave for their helpful comments on drafts and to Garry Bodenham for recording the interview with Tommy. Also to Monique Petit, Louise Ramage and Emma Pattison for help in editing.

Introduction

It is a curious experience to have written a book during a time when the government was expected to change after many years, knowing that if that change came, many of the policy aspects of the book were likely to change as well, and the documents we refer to may fairly soon become unavailable. Organisations we refer to may also disappear. In addition, clinical guidance is also continually being updated and although we have used the most up-to-date guidance in this book, we are aware that this may soon be superseded and we would direct you to check for any updates.

As we write this Introduction, we do now know the new government's plans for the NHS, as the white paper, *Equity and Excellence: Liberating the NHS* appeared in July 2010. The most commented-upon intention is the devolution of health care commissioning in England to consortia of GPs and the abolition of primary care trusts and strategic health authorities – a high-risk strategy which may exacerbate health inequalities, since the quality of general practice is worst in many areas where the social disadvantage is greatest. There is, however, a stated aim in the white paper to put patients and the public first, in particular by making shared decision-making the norm: *no decision about me without me.* This fits well with the ethos of this book and supporting people with long-term conditions (LTCs).

There has also been much discussion about the election pledge ‘the Big Society’, in which communities will be encouraged to take action on problems rather than relying on the state; how this will work when many third sector organisations will be getting less funding remains to be seen. Local authority budgets will also be greatly

reduced, putting the interface between health and social care at risk. In addition, public health measures such as minimum pricing for alcohol and improvements in food quality have been rejected, so we may return to an individualistic approach to public health, rather than the societal approach referred to in the discussion on health inequalities in our book.

Despite the future changes and the number of ‘unknowns’, the heart of the book, which is the experiences of people with LTCs, and the need for us to provide the best care we can, will not change. The demographic pressures of an older population, and more people developing LTCs, will remain, as will the complexity of care and support which many people need. In order to do justice to our subject, we have concentrated on the care of adults and on physical illnesses, although we recognise the importance of mental illness and the difficult interrelationship between social disadvantage, physical illness and mental illness, particularly depression.

The discussion in this book moves from a global and national perspective on some of the issues around LTCs, in chapters 1–3 (‘Long-term conditions in perspective’, ‘Case management’ and ‘Changing approaches to the management of long-term conditions’), to a more personal and individualistic approach to supporting people living with an LTC with chapters and 5 (‘Sociological insights’ and ‘Psychological effects of long-term conditions’) focusing on the effects that living with an LTC can have on individuals and their families. We also move from a generic approach to the care and management of people with LTCs in chapters 6–10, with many issues pertinent to all LTCs, to a more specific and clinical focus on three main LTCs in the final three chapters.

Due to the scope of this book, we have used a range of terminology according to the chapter focus and terms that are more commonly used. To this end, we have used such terms as illness, long-term conditions and chronic illness throughout the book, and referred to patients rather than people when more appropriate to do so.

The aim of this book is for nurses to gain a wider perspective on the issues and experiences of people who are living their life with LTCs. We are keen for the focus to be on the person with an LTC and the management and care of their condition to be aimed at enabling the person to live their life as they choose. With this aim there becomes not one truth for the best way to manage specific LTCs, but many truths which are individual to each person. These truths need to be understood and respected, and used *with* clinical knowledge to plan and manage care. To this end, the focus must be for nurses to develop a true partnership with people living with LTCs based on acceptance, empathy and respect. This involves nurses listening to people's stories and valuing their personal and unique understanding of their condition and how they manage their life with this.

Liz Meerabeau
Kerri Wright

Chapter 1

Long-term conditions in perspective

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Introduction

All developed countries, whatever their political system and overall approach to health policy, face challenges in meeting the rising costs of health care. This increase in health care costs generally exceeds the rate of economic growth; contributing factors include increasing proportions of older people in the population, the development of expensive medical technologies and drugs, and increasingly well-informed people who demand access to these developments in health care. *High Quality Care for All* (Department of Health, 2008a), also known as the Darzi Report after the junior health minister who led the NHS Next Stage Review, identifies six challenges common to all advanced health care systems: rising expectations, demand driven by demographics, the continuing development of the 'information society', advances in treatments, the changing nature of disease and changing expectations of the health workplace (i.e. staff expect a better work-life balance).

An important element of the changing patterns of disease is the increase in prevalence of long-term conditions (LTCs); LTCs are one of the eight priorities for the NHS. Dowrick *et al.* (2005) consider that the management of what they term chronic illness is beginning to develop its own identity as an important component of health care, and that despite clinical differences, there are many similarities in the problems people with different LTCs face and the strategies needed in providing care. These include the proactive identification of relevant populations, supporting the relationships between people with LTCs and health and social care, the development of evidence-based guidelines intended to prevent exacerbations, and the promotion of empowerment, for example through self-management.

This chapter discusses changes in the need for health care due to demographic change and persistent inequalities in health, before going on to outline some of the changes both in service delivery generally and in the provision of health care for LTCs more specifically, such as the use of targets by governments, and the growth of patient-focused care. Generally, like the rest of this book, the chapter has an English focus, in which policy initiatives and service developments include user participation (Department of Health, 2003) and National Service Frameworks (NSFs) with specific standards, for example for coronary heart disease (Department of Health, 2000a) and for LTCs (Department of Health, 2005a). Comparisons with the other three UK countries are also made briefly, and the global context is also discussed.

The global challenge: demographic change

Within the overall trend towards older populations, the most rapidly growing segment is that of people over 80: the Organisation for Economic Co-operation and Development (OECD)(1988) estimated that whereas in 1980 the cohort of older people was made up of 34% aged between 65 and 69, 48% between 70 and 79 and 18% 80 or over, by 2050 these percentages would be 26%, 43% and 31%, respectively.

More recently, *An Ageing World: 2008* (US Census Bureau, 2009) highlights a huge shift to an older population, with great consequences. In the next 30 years, the number of people over 65 in the world will almost double to 1.3 billion, and in 10 years time, older people will outnumber children for the first time. This will affect family structure, patterns of work and retirement. Europe has 23 of the 25 ‘oldest’ countries in the world (including all of the countries of western Europe, with the exception of Ireland and Denmark). In the United Kingdom, the nineteenth ‘oldest’ country, by 2040 there will be 46 people aged 65 and over for every 100 people of working age (defined as aged 20 to 64); in Germany, the figure will be 58, and in Japan, 68. (This ratio is called the older dependency ratio.) This compares with 16 in South Africa and 23 in India. Japan, Singapore, France, Sweden and Italy all now have life expectancies at birth of more than 80 years. However, although the proportion of older people in the populations of developing countries is much lower, because of the size of these populations, overall most of the increase in the number of older people in the world is actually in these poorer countries. China is one of the fastest ageing countries in the world, since its fertility rate has been below the replacement

rate since 1991, due to its long-standing one-child policy. In Japan, 22.5% of the 127 million people are over 65, whereas only 13% are under 15.

It should not be assumed that greater longevity automatically increases the burden of ill health; many people are likely to live relatively healthy lives until their last few years, although it is likely that they will be managing one or more LTCs. The Academy of Medical Sciences (2009) report *Rejuvenating Ageing Research* states that in the United Kingdom healthy life expectancy is increasing at least as quickly as overall life expectancy. Far fewer older people are disabled than was the case in the 1970s, and drug treatments for hypertension and cardiac problems have reduced the mortality from heart disease by 40% since the 1990s. Older people in many countries also contribute towards society in that they pay considerable tax and are major providers of care, both to children and to other older people. Nevertheless, the ageing of the population does result in higher health care costs. In most countries, people over 65 account for at least twice the health care expenditure that their proportion in the population would predict; in the United States, people over 65 constituted one-eighth of the population in 2000, but consumed nearly half of the health care expenditure (the UK figures were one-sixth and 43%, respectively). The OECD (1988) projection was that these figures for expenditure would rise to 63% for the United States and 54% for the United Kingdom, by 2040. Appleby (in Pilkington, 2009) estimates that the NHS needs about 1.5% extra funding every year just to cope with increased need due to demographic change.

The demand for health care

A second important factor in driving up health care costs is the growth of expensive medical interventions. Many medical innovations have not been fully assessed in terms of costs and benefits, although health technology assessment for potential new interventions is well established in Australia, Sweden, the Netherlands, the United Kingdom and the United States (in individual states such as Oregon, which was a pioneer in health technology assessment). In England, such assessment takes place through the National Institute for Health and Clinical Excellence (NICE). The costs of health technologies are assessed against the benefit, which is calculated primarily by means of quality-adjusted life years (QALYs). This measure has proved controversial; treatments for the terminal stages of diseases such as kidney cancer are likely to fall short of the threshold for NHS funding, since life expectancy is short, and in some instances QALYs have been recalculated to allow for this. Although NICE was set up to try to depoliticise decisions about expensive medical interventions, there has been intense lobbying in response to its decisions, and there is concern that services for other less vocal people, such as mentally ill or older people, may get displaced as a result. Arguments about the entitlement to treatment are likely to be tested in the courts, for example in 2006 in relation to Herceptin, a drug for certain types of breast cancer.

It has been recognised that a small percentage of people consume a large percentage of health care resources; therefore, managing LTCs has become an important element in health policy, both for humanitarian reasons and in an attempt to control costs. In England, one-third of the adult population has an LTC; in some areas this rises to half (Department of Health, 2008b). Even in younger age groups, 15% of children under 5 and 20% of children and young people aged 5–15 have an LTC

(Wilson *et al.*, 2005). The British Household Panel Survey (2001) found that people with LTCs accounted for 80% of GP consultations; they also account for 72% of inpatient days in England and 65% of outpatient appointments (Haddad *et al.*, 20092009). By 2030, the incidence of LTCs in people over 65 is estimated to more than double (Department of Health, 2005b). People with long-term physical conditions also have a 20% risk of depression, a rate which is two to three times higher than that for people in good physical health (Egede, 2007).

Globally, the most common LTCs are cardiovascular diseases such as hypertension, coronary artery disease, stroke and heart failure, various forms of arthritis, respiratory problems, diabetes and epilepsy; such illnesses contribute to nearly half of the prevalence of disability worldwide. HIV/AIDS has also become an LTC in countries where there is adequate treatment. Mental health problems such as depression are also increasingly viewed as LTCs. LTCs are collectively the largest cause of death globally (World Health Organisation, 2005), despite the prevalence of infectious diseases in poorer countries; by 2025, an almost 300% increase in deaths from ischaemic heart disease and stroke is predicted in Latin America, the Middle East and sub-Saharan Africa (Yach *et al.*, 2004). Chronic obstructive pulmonary disease is predicted to be the third main cause of death globally by 2020 (Murray and Lopez, 1997). About 2.8% of the global population has diabetes; this is likely to increase to 6.5% by 2030 (Murray and Lopez, 1996), and is linked to the increased incidence of obesity.

If current trends continue, 60% of men, 50% of women and 25% of children in the United Kingdom will be obese by 2050 (Foresight, 2007); excess weight is increasingly seen as the norm. It is beginning to be recognised in the United Kingdom that the environment is obesogenic, for

example due to the availability of cheap, high-fat food, and that government intervention has not so far been effective; the chair of the International Obesity Task Force, Professor Philip James, gives the current English campaign, Change4Life, only a 10% chance of success (Dent, 2009). Change4Life is an example of a recent approach to addressing health-damaging behaviours which has been adopted from the United States, social marketing. A national centre for social marketing, a collaboration between the Department of Health and the National Consumer Council, was launched in 2006. The aim is not only to raise awareness but also to equip people with ways of changing their behaviour, using solutions which meet their needs, and where necessary, to change policies and structures which reduce people's capacity to live healthily.

As the example of obesity illustrates, reducing mortality and morbidity from LTCs requires individual engagement with lifestyle factors; Wanless (2002) has termed this the ‘fully engaged’ scenario, in which individuals take responsibility for their own health, and public health goals such as smoking cessation are achieved. If this scenario is not achieved, the costs of health care will become unaffordable. Public bodies also have a key public health role. *High Quality Care for All* (Department of Health, 2008a) refers to the legal duty for the NHS and local authorities to work together to address public health issues, and to cooperate in improving outcomes for their populations, on the basis of a formal assessment of people's needs (Joint Strategic Needs Assessment). These plans involve other agencies, such as the police, and focus not only on health priorities such as smoking but also on broader factors such as poor housing, education, local transport and recreational facilities.