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# Introduction

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*Elaine Denny and Sarah Earle*

It is a frequently repeated saying that people are living longer, yet living at least some of those extra years in poor health. The reasons for this longevity are mainly the result of environmental factors such as improved living standards, a cleaner environment and better nutrition resulting in a reduction in the major causes of mortality of previous eras. Yet it is not just older people who are surviving illness that would have proved fatal in the past. People of working age, children and young people are also living with diseases and following injuries that would have proved fatal as recently as one generation ago. Diseases such as cancer and HIV, which used to be considered a death sentence and survivors being thought of as incredibly lucky, are now being managed for many years, with those affected being able to live a life that can range from near normal to severely incapacitated. Similarly, premature birth was frequently followed by premature death, but now neonatal care means that many of these babies survive. However, predictions about how much, if any, disability such children will experience are difficult to make. So improvements in survival are making new demands on the health care professionals who work with those affected by long term illness and disability; and nurses are in the vanguard of attempting to address them.

Those people with multiple conditions are disproportionate users of health services. People with long term conditions visit their General Practitioner (GP) more frequently, experience more hospital admissions and stay in hospital longer than the rest of the population (Wilson, Buck and Ham, 2005). A high proportion of emergency hospital admissions and of total bed days are for exacerbations of long term illness (DH, 2004). The major health concern of the twenty first century, therefore, is

not the acute illnesses which the NHS and most Western health care systems were set up to deal with, but the management and improvement of the quality of life for those living with a condition or disease for which there is no cure. The policy challenge is to move away from a health care system based around acute episodes of ill health to one that supports those with long term illness in appropriate care settings. A further challenge is that long term conditions tend to be disproportionately found in the most disadvantaged sections of society, and a reduction in health inequalities is also necessary in order to reduce their incidence.

From the above discussion we can begin to understand renewed government interest in long term conditions and a move from hospital to primary and community care as the focus of health care. Nurses are pivotal to this move, expanding their roles in areas such as non-medical prescribing and the role of Community Matron. When people are not managed effectively they use physical, emotional, and financial resources that would not be necessary if problems were prevented or diagnosed early. Their own expertise in managing their condition – built up from personal experience – supplemented by the research that many people carry out, is not utilized to the best effect. They are not treated as partners in their care, and their quality of life suffers. It is the recognition of these factors that has focused governments' health agenda on better ways of managing those with long term illness.

Some of these issues have been highlighted by the work of policy analysts and sociologists of health and illness over many years. Raising them here demonstrates that nurses working in this area need more than just their clinical knowledge of the illnesses that they confront. They also need to be able to engage in the debates about the most appropriate delivery of care to their client groups, and to see their work in a broader context. This book utilises classic sociological work and more recent empirical evidence to produce a sociology of long term conditions that reflects the contemporary situation.

In common with other volumes in the *Sociology for Nurses* series this book demonstrates the ways in which a sociological imagination can inform and enhance nursing practice in the context of a changing health service. Nurses are in the forefront

of caring for people with long term conditions both in hospital, in the community and other settings; yet most existing textbooks focus on the sociology of disability, and are not specifically written for nurses. While acknowledging the importance of this work, this volume places emphasis on the application of the sociology of disability *and* chronic illness to the practice of nursing people with long term conditions. The book is divided into two parts. Part I focuses on theory, policy, and research relating to chronic illness and long term conditions. Part II examines a range of long term conditions exploring how the development of a sociological imagination can enhance nursing practice in this field.

We have in this introduction been using the terms ‘chronic illness’, ‘long term illness’, and ‘long term conditions’ interchangeably. Partly, this reflects changing terminology over the years. Early work from whatever academic discipline spoke of chronic illness, which was taken to mean long lasting and incurable. This was contrasted with acute illness which was short term, and self limiting or curable. A problem with this term is that for some people for some of the time they are not ill, their condition relapses and goes into remission, but does not go away. ‘Chronic’ too does not adequately describe something that is characterised by acute flare ups. On the other hand many people are ill for a lot of their lives, they have symptoms that need treatment or some form of health intervention, so ‘condition’ does not sufficiently reflect their situation. Recent government initiatives have used the term ‘long term conditions’, for example in the National Service Framework for Long Term Conditions (DH, 2005). Long term conditions are defined on the Department of Health website as those conditions that at present have no cure, but that can be controlled or contained by medication or other interventions. There is not, however, any rationale given for the change to current terminology, nor indication of any dissatisfaction expressed about the continued use of the term chronic illness. Even amongst the authors of this book there has been disagreement over terminology. However, this disagreement has been characterized by a concern for the most appropriate terminology for the particular group of people that the author is writing about. As editors we have left the terminology to the discretion of individual

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authors within their own chapters, and of course when quoting or citing work the discourse of the original author has been employed. For the title of the book, however, we have decided to adopt the term ‘long term conditions’ since it most accurately reflects contemporary use, and has the most currency within policy and nursing practice.

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