Translating Chronic Illness Research into Practice

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Preface

The purpose of this book is to provide both a synthesis and a critique of recent advances in chronic illness research and to consider the applicability of that research to chronic illness prevention, treatment and care. The aim has been to present an overview of recent chronic illness research and to profile examples of the applications of such research in clinical practice.

Health care does not occur in a vacuum, but is intrinsically linked to politics, environment, culture and society. Globally, it is a fact that no country will have sufficient resources to address completely the health-care wants and needs of its people. Increasingly, we need to think globally but act locally using the best evidence available as an indicator of effective care intervention. Researchers and practitioners alike are aware that if research is to inform chronic illness prevention, treatment and care, it must be studied in ways that acknowledge the complexity of the chronic illness experience and transcend the boundaries of the relationship between the person with the illness and the health-care provider. Provided in this book are detailed examples in which interdisciplinary, transdisciplinary and multidisciplinary teams of researchers have developed initiatives that have been successful in assisting people with chronic illness to live well. However, many of these initiatives may be unknown to health-care practitioners who have confined their reading of research-based evidence to journals and texts in their own language, discipline and/or nation. The editors of this book have brought together internationally renowned researchers in chronic illnesses to present an overview of recent advances and to suggest future directions in chronic illness research, prevention, treatment and care.

To achieve the purpose of translating chronic illness research into practice, we focus on the key concepts of chronic illness, practice, research on chronic illness and translating research into practice. Within the book, several authors define chronic illness as they have interpreted it for their chapters. The concepts of translation and practice are defined as follows: ‘Translation research transforms currently available knowledge into useful measures for everyday clinical and public health practice’ (Narayan et al. 2004, p. 959).

The gap between research and practice is well recognised and this book illuminates some of the complexities of applying evidence to practice, and through these discussions aims to make a contribution to bridging this gap and thus is
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a resource to others wishing to underpin their practice with research. ‘Practice’ refers to the integration of knowledge and/or theory about health promotion, chronic disease prevention, the management of chronic illness or the experience of living with chronic illness in the performance of a clinical, research or policy development role. A wide range of research that is of relevance to chronic illness has been presented and authors have either provided a critique or an interpretation of its potential utility or limitations for application to practice. In this way, this book is making relevant research available to users and also illustrating how it might be, or indeed has already been, used in the fields of health promotion, clinical management or policy making.

Chapter 1 sets the scene by developing our understanding of chronic illness research globally, and then serves to identify barriers and enablers to advancing knowledge about prevention and management of chronic illnesses. The need is identified for a universal understanding of the chronic disease experience that goes beyond the biomedical perspective to build a stronger foundation for health promotion and disease prevention initiatives.

Transition, as a chronic illness experience, is the focus of Chapter 2. An overview of the different conceptualisations of transition is provided, detailing areas of ambiguity in the research. A transition framework relevant for health practice when working with people with chronic illness is detailed.

Chapter 3 explores the translation of chronic illness research across the lifespan of a person. It highlights the relevance of a developmental perspective on chronic illness in order to understand how chronic illness and human development interact to impact on the life of individuals and families across the lifespan. A review is provided of central tenets of the human development perspective, followed by a brief review of the current state of affairs with regard to applying a lifespan developmental perspective in chronic illness research. Finally, examples of chronic illness research informed by a lifespan developmental perspective are reviewed.

Chapter 4 provides an overview of how co-morbidity has been conceptualised within the various health-care disciplines, which has contributed to the fragmentation, replication and omissions in care of people with co-morbidities. The inequities in health care and the influences of the social determinants of how people with co-morbidity respond to and manage their health are also discussed. The debate about how best to manage multiple chronic illnesses from the various stakeholders is highlighted, drawing attention to the need for longitudinal approaches to health-care delivery to ensure continuity of care.

The international, historical and policy contexts of self-management are explored in Chapter 5. Concepts are described, which overlap with or inform an understanding of self-management from both the person’s perspective and the health professional’s perspective. This chapter also broadens our understandings of self-management concepts and practical applications of these.

Chapter 6 is a synthesis of published international research about self-management interventions within the field of type 2 diabetes. It presents a critical view of the self-management education and/or behavioural support interventions that have been reported in the published literature for the purpose of
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revealing how the way the interventions have been framed by researchers has influenced who chooses to participate and to remain in the intervention.

The focus of Chapter 7 is the emergence of technology for supporting patients and their families. An overview of research is provided regarding the use and outcomes of technology in fostering the self-management of chronic illness, including locating and discussing gaps and areas of ambiguity in current work.

Finally, Chapter 8 looks to the future of chronic illness and chronic illness research. It explores how we might positively modify future projections of chronic illness by building upon the revolution that is happening in some parts of the globe in knowledge translation.

Practitioners and researchers across the globe have much to learn from each other and enhancing this communication would benefit all parties. The growing burden of chronic illness – both communicable and non-communicable – across the world and creative responses by researchers in various disciplines to those challenges can provide important lessons (and research opportunities). This book is intended as a text and resource for researchers and practitioners across health disciplines as well as for graduate students within the health professions and the social sciences. It will also inform academic researchers, government policy experts, health plan and consumer representatives regarding available research in the field.

We anticipate that this book will contribute to the dialogue and debate that focus on and explicate our knowledge and the different ways of knowing in chronic illness research and practice. It has been a privilege to work with the contributing authors and to experience their commitment to the care and well-being of people living with chronic illness.

Debbie Kralik
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Reference

1. Globalisation of Chronic Illness Research

Sally Wellard

Introduction

This chapter builds on my previous work (Wellard 1998) where I have explored discursive constructions of chronic illness and argued that discourses of science, individualism and normalisation underpinned our ways of working with people experiencing chronic illnesses and the research questions that are posed. The aims of this chapter are (a) to develop a contemporary understanding of chronic illness research globally and (b) to identify barriers and enablers to advancing knowledge about prevention and management of chronic illnesses.

A review of contemporary literature identified a number of significant shifts that are relevant to the aims of this chapter, most notably the recognition of chronic illnesses as an urgent problem affecting global health. Discourses of science remain evident, but an increasing emphasis on economic and social consequences of chronic illnesses is emerging. There are a number of challenges in attempting to gain a global view of work in the field of chronic illness. First, the literature surrounding chronic illness is vast and the volume of material is overwhelming. Second, the analysis presented in this chapter is limited by my reliance on the English language. Although there is considerable work related to chronic illness published in many other languages, it was not accessible to me. Third, there are limitations in the databases available for bibliometric analysis by researchers. For example, Hofman et al. (2006) identified that MEDLINE ‘does not equally represent all countries, journals or topics’ (p. 418), resulting in a poor or inaccurate representation of research in middle- and low-income countries.

The strategy adopted for developing a contemporary view of the globalisation of chronic illness work was to develop an integrative literature review with the goal of developing a critical analytical view of trends in the field. GOOGLE scholar (http://scholar.google.com/) and MEDLINE database (using PubMed: http://www.ncbi.nlm.nih.gov/sites/entrez/) were searched, identifying the range of literature published between 1995 and 2007. Additionally, a search of the World Health Organization (WHO) web pages (http://www.who.int/en/)
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revealed relevant reports and links. The main search terms used were chronic illness, chronic disease, research, management and prevention. References in recently published work were scrutinised, and textbooks were hand searched.

What is in a name?

The first striking feature in reviewing recent literature related to chronic illnesses is the variety of terms that are frequently used as synonyms for chronic illness with little acknowledgement of the meanings implied in their use. Predominant terms identified included chronic illness (CI), chronic disease (CD), chronic conditions (CC), non-communicable disease (NCD) and chronic illness and disability (CID). Terminology matters, and the absence of a clear definition can blur meanings and assumptions inherent in the arguments presented by authors. Gerber et al. (2007) also noted the scarcity of a conceptual definition of disease and illness, raising concerns about adopting recommendations from research without understanding the premises on which such investigations are based.

The interchangeable use of the terms disease and illness is not new. Larsen (2006) argued that differentiation between these terms is important. Disease refers to the practitioner’s view of pathophysiological alterations in a person’s condition, associated with an objective medical view of a human ailment (Hofmann 2002) and the assignment of a diagnosis (Wikman et al. 2005). Illness, however, refers to the perceived human experience of living with and responding to disease by those with the disease and the people who live with them (Taylor 2005; Larsen 2006). Illness is frequently referred to as a subjective interpretation of disease (Hofmann 2002). These terms are broad and imprecise (Wikman et al. 2005); they could refer to minor conditions with low impact or very serious conditions with life-limiting effects.

The concept of chronicity, most simply defined, relates to the temporality of a condition where changes in health are ongoing and will not be cured by a short course of treatment or surgery (Miller 2000). Various publications attempt to create more specific detail, but there remains little consensus around a more precise definition. Some authors indicate that a chronic illness must have a duration of more than 6 months (O’Halloran et al. 2003), whereas others are less specific, with greater focus on the ongoing nature of illness and the accompanying complexity and adjustment in daily life as criteria denoting chronicity (Price 1996).

The terms chronic disease and chronic illness remain the most commonly used. Another term found in the psychological literature, chronic illness and disability (CID), is of interest in this discussion because it assumes a coupling of illness and disability (Livneh 2001). Livneh and Antonak (2005), rather than defining CID, list characteristics commonly associated with CID to include some functional limitations and an effect on capacity to carry out daily activities; uncertain prognosis and a long-term need for medical and rehabilitative care; experience of psychosocial stress related to the condition; impact on family; and sustained financial loss (p. 12). This definition would exclude some common chronic ailments, such as hypertension, where there is often little or no impact on daily activities.
Globalisation of Chronic Illness Research

The recent emergence of new terminology appears to be an attempt to create an umbrella term that will be inclusive of the different understandings of chronic ailments and link different audiences to look more at the overarching issues related to chronicity in the world. For example, the term *chronic conditions* (CC) now frequently appears in Australian literature, used by the federal government agencies, and is often used interchangeably with chronic disease. For example, O’Halloran et al. (2003), in a report for the Australian Institute of Health and Welfare, defined chronic conditions as those lasting at least 6 months, showing a pattern of deterioration or periods of relapse and remission, having a poor prognosis or possible lack of curability and disease-related effects, including co-morbid conditions. The use of the word *condition* is increasingly visible in programmes that engage different stakeholders (consumers, health-care professionals and educationalists) who are sponsored by the Australian Department of Health and Ageing.

The term *non-communicable disease* (NCD) appears in many publications related to international discussion across a number of sectors (e.g. the WHO, United Nations and World Bank). Although the term is increasingly used in literature, there remains little definition and an implicit assumption that these terms are commonly understood. Non-communicable disease does focus attention away from infectious diseases but remains contentious as a descriptor for chronic illness/disease because some infectious diseases can also be chronic (e.g. malaria).

In this chapter, the term *chronic illness* has been adopted to refer to ongoing alteration in health, except where I am specifically addressing a particular disease or group of diseases, or representing the arguments of others.

Global crisis in chronic illness

Until recently, popular understandings of global health were dichotomised. Chronic illnesses were generally portrayed as ailments of the populations of developed countries (e.g. heart disease, diabetes and cancer) and associated with affluent lifestyles leading to increased risks linked with energy-dense high-fat diets and inactivity. Conversely, infectious diseases were largely portrayed as ailments of developing countries (e.g. bacterial and viral diarrhoeal diseases) associated with poverty and insufficient infrastructure to prevent their spread. The United Nations Millennium development goals adopted in 2000 reflect that dichotomised view, with a focus on addressing factors that will reduce the incidence of infectious diseases (more details of the goals are available at http://www.un.org/millenniumgoals/).

This dichotomised view has recently been challenged with increased attention to what is argued by many as a global epidemic of chronic disease (Horton 2005). The WHO estimates that death from chronic diseases in 2005 is double the death rate from the combined causes of infectious diseases, perinatal and maternal conditions and nutritional deficiencies (WHO 2005). The global distribution of mortality from chronic illness has significantly changed, with 80% of deaths
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from chronic illnesses now occurring in low- and middle-income countries (Strong et al. 2006).

The change in prevalence of chronic illness has been associated with the increasing ageing of the world’s population. Strong et al. (2005) estimated that ‘all chronic diseases account for 72% of the total global burden of disease in the population aged 30 years and over’ (p. 1579). This represents a significant burden not only for individuals and their families but also high economic and social costs for countries (WHO 2005). The WHO Global Report (2005) identified cardiovascular diseases, cancer, chronic respiratory diseases and diabetes as the leading contributing factors to the chronic illness epidemic. In many low- and middle-income countries, these diseases occur more commonly in younger adults than in high-income countries and result in earlier mortality. Chronic illness does not exist only among adults; there has been a worldwide increase in childhood obesity in the past decade in low-, middle- and high-income countries, with an associated rise in the prevalence of type 2 diabetes in children and adolescents (WHO 2005).

The risk factors of many chronic illnesses are well known. They are considered modifiable and include unhealthy diet, physical inactivity and the use of tobacco (WHO 2005). However, these risk factors associated with lifestyle are complex to address. Strong et al. (2005) argue against the common myth that unhealthy behaviours are related to poor choice of individuals, directing attention to the interplay of environment, economy and increasing urbanisation being influential in poor diet and limited access to activity in low- and middle-income countries. The influence and impact of chronic illness differs across the globe and similarly the emphasis in research differs.

Impact of chronic illness in developing nations

Research related to chronic illness in developing countries (low and middle income) has a strong emphasis on measuring the prevalence and impact of chronic illness, using mortality and disability-adjusted life years (DALYs) as indicators of the burden of disease (Strong et al. 2005). The growth in population-based health surveillance studies has facilitated a commensurate growth in research, expanding knowledge and understanding about the social determinants of health. The investigation of the burden of disease has been undertaken for many decades, but has recently received greater prominence with the development of more sophisticated methodologies and improved access to data sets, facilitating a global analysis of information at the population level. It is now possible to link incidence of disease with both short-term and long-term health outcomes and with mortality (Mathers et al. 2001). Morbidity is assessed using DALYs, where ‘one DALY can be thought of as one lost year of healthy life and the burden of disease as a measurement of the gap between current health of a population and an ideal situation where everyone lives to old age in full health’ (Strong et al. 2005, p. 1579). The Global Burden of Disease study (WHO 2005) now represents analysis across a greater number of low- and middle-income countries with more
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detail, including information relating to educational levels. This global study provides baseline data from which effectiveness of interventions can be evaluated and further analysis of changes in distribution of mortality and burden of disease across countries can be made.

The goal of this chapter is not to discuss the status of any specific chronic illness; however, the level of obesity in low- and middle-income countries is striking and therefore will be briefly presented. Prentice (2006) reviewed the epidemiological data on obesity and reports that the obesity ‘pandemic is penetrating the poorest nations in the world – first amongst the urban middle-aged adults, but increasingly affecting semi-urban and rural areas, and younger age groups’ (p. 93). His examination of Gambia as a case study revealed significant differences in rates of obesity within the country, although the overall rate of obesity for the country was relatively low at 4%. Women were significantly more obese than men, with 32% of women over 30 years being obese, compared to less than 2% of males. Additionally, obesity was higher in urban-dwelling people. While childhood malnutrition remains a concern in developing countries, there is also an emerging incidence of childhood obesity in these countries. Poverty, reduced access to quality foods and limitations on physical activity associated with overcrowded urban developments are considered to be contributing to these changes in childhood obesity (WHO 2005).

There has been rapid expansion in the study of social factors associated with poor health. The seminal work of Doyal and Pennell (1979) exploring the political economy of health demonstrated that ill health is not solely related to medically defined causes, but is a product of inequalities arising from the social and economic organisation of society. In the past decade, considerable research has explored and expanded our understandings of what are now commonly referred to as the social determinants of health (Irwin et al. 2006). Gross inequalities in health have been identified within and between countries (Marmot 2005). The establishment of the Commission on Social Determinants of Health (a WHO initiative) in 2005 is an active strategy to advance systematic research to reduce health inequities in partnership with individual low- and middle-income countries (Irwin et al. 2006). Poverty and inequity in consumption of resources underpin the social determinants of health (Judson 2004). Poverty is linked to social status, race, gender and education. Wilkinson and Marmot (2003) summarised the social determinants of health into 10 key areas to inform action to address inequities: the social gradient, stress, early life, social exclusion, work, unemployment, social support, addiction, food and transport. Broad-based action, rather than medical-specific action, is clearly indicated to address the social determinants of health. Continuing to invest in medically driven health services without concurrent attention to these factors will have little impact on the overall rates of chronic illness. For example, Le Gales-Camus (2005) argued that banning tobacco advertising and increasing taxes on cigarettes are effective preventative strategies against tobacco-related cardiovascular disease and cancer and are needed in low- and middle-income countries. This type of strategy has a much greater impact on reducing the rate of tobacco-related disease and reduces the subsequent demand for high-cost medical services. Prevention is considerably less expensive than treatment, but systematic
preventative health programmes are limited in their effectiveness by inconsistent
distribution in many countries.

**Trends in chronic illness research in developed nations**

Understanding the prevalence and impact of chronic illness remains part of the
research agenda in high-income countries; however, given their greater resources,
a number of additional areas of research related to chronic illness are prominent.
There is now considerable understanding of the sociological aspects of living with
chronic illness that has influenced the growth in the work exploring connections
between peoples’ experience of illness and the ways in which they can be
supported in that experience (Taylor & Bury 2007). There is extensive literature
about the meaning and significance chronic illnesses have for individuals and
their families across a wide variety of diagnoses (e.g. diabetes, renal disease and
multiple sclerosis [MS], to name a few). Thorne and Paterson (2000) referred to
this area of research as *insider research*, which has included exploration of bodily
experiences of illness (Kelly & Field 1996; Wilde 2003), the impact of living with
illness on people’s social worlds (Livneh 2001) and their experiences of stigma
and social exclusion (Wellard & Beddoes 2005; Lubkin & Larsen 2006). There is
a clear acknowledgement of the importance of illness narratives to people living
with chronic illness (Charmaz 2000; Werner et al. 2004).

Personal accounts or narratives of illness experiences have facilitated increased
understandings of the multiple ways in which people respond to chronic illness
and develop personal approaches to assist them in living with the illness and its
effects (Wellard 1998; Mengshoel & Heggen 2004). Hardy (2002) documented the
diversity of ways in which narratives are expressed among those with chronic
illness, and the way the Internet has been appropriated by many people to extend
the form of their narrative expression. The Internet has expanded the available
space for narratives, and the use of ‘home pages’ now provides a dynamic
and potentially interactive space for moving beyond accounts of individual
experiences to places where people also provide advice and, in some instances,
advocate particular approaches to care. It is likely that growth in the provision
of advice via the Internet will expand further with ‘e-commerce’, facilitating
increased individual marketing of advice globally (Hardy 2002).

Another focus of recent research has been to understand the transitions that
occur in the lives of people with chronic illnesses and how people respond and
adapt to these transitions. Kralik et al. (2006) argued that transitions involve a
change over time where the persons reconstruct their self-identity. Transitions
for people with chronic illness are not linear and are differentiated from earlier
work on illness trajectories that suggested predictable pathways and stages in
disease progression (Wellard 1998). Transitions are triggered by turning point
events (Rasmussen et al. 2007) and for people with chronic illness, these can be
predictable or unpredictable, cyclical and potentially recurring throughout life
and result in the persons redeveloping their ways of living with illness (Kralik
2002). In a recent study of young women with diabetes, relationships with people,
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both social and with health professionals, were found to be important in managing transitions successfully (Rasmussen et al. 2007).

The complexity of, and variable quality in, relationships between people with chronic illness and professionals in the health-care system have been widely reported and arguably contribute to a level of difficulty for many in managing their illness (Thorne 2006; Wellard et al. 2007). Frequently, health professionals act as gatekeepers of health services, effectively controlling access to resources. This is in part due to a need to ration resources but it is also a reflection of the authoritative power of professional knowledge within our current systems (Clapton & Kendall 2002; Thorne 2006). More recent challenges to the assumption of the health professional being the expert suggest the need to recognise that patients are experts in their own right; this recognition is an important part of building successful partnerships in health-care provision. Fox (2005) summarised the debate in identifying the forms of expertise that both patients and professionals bring to the health-care relationship. Patients have expertise in the specific experience of their illness, their social situation, the levels of risk they are prepared to accept, their own values and preferences for living and treatment choices. Health professionals bring expertise in general understanding of disease (including aetiology, diagnosis and prognosis), the available treatment options, associated risks and probable health outcomes. Both levels of expertise and perceptions of that expertise vary among patients and professionals (Fox 2005).

There has been a shift from the use of the label *patient* when referring to people with chronic illness to the label *consumer* in some literature. There are a number of different constructions of the term *consumer* within the chronic illness field. Consumer groups bring together interested people associated with a specific illness or group of illnesses (including patients, carers and professionals) to provide a public voice about the issues and concerns of the members (Allsop et al. 2004). For example, in Australia, the Chronic Illness Alliance has represented over 40 consumer and advocacy groups on matters of common concern to promote the interests of those with chronic illness to the government, health professional groups and health service providers. The MS society is an example of a single illness focus consumer group that lobbies for resources, funds research and provides services specifically to people with MS. Consumer groups like these have the potential to influence policy and services that are more responsive to the needs of people with specific chronic illness.

The term consumer has also been used to refer to those people who use health-care services. The term is associated with a broader change within Western societies where ideologies of privatisation and market predominate (Allen 2007). Increased access to information has led to consumers being well informed and knowledgeable about their rights, including the right to be treated fairly in transactions and the right to purchase and consume what they desire. Consumers of health-care services have also become better informed about medical knowledge and treatment options (Woolf et al. 2005). However, Walker (2007) argued that the underpinning assumption that all consumers have equal capacity to choose and participate is fallacious because choices in health consumption are greatly
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influenced by individual circumstances including income, geographical location and disease severity.

Part of the consumer focus in health care has been the introduction of consumer models of care where partnerships between provider and consumer aim to deliver better outcomes; however, there are a number of impediments to engaging in consumer partnerships in health (Wellard et al. 2003; Penney & Wellard 2007). Barriers to engaging in partnerships for care with consumers are diverse and reflect the often experienced gap between espoused ideals and practical realities of health service delivery in a constantly evolving system where innovation frequently outstrips the resources to support it. While recognising the shift towards consumerism, the structures of health-care services continue to position users of services as patients who rely on professional expertise, frequently reconstructing paternalism as a silent foundation for professional practice.

Patient-centred care has been argued to be a cornerstone of health-care practice and identified as a shared value among health professionals where practice is guided by principles of what is ‘good’ for patients and their families (McGrath et al. 2006). Patient-centred care implies that care focuses on the persons as a whole, not only on their disease and symptoms, and therefore it requires partnerships between health-care professionals, patients, their family and caregivers. Partnerships arguably lead to improved health outcomes and increased levels of satisfaction for all stakeholders. However, there is increasing recognition that involving people in partnership for care is highly desired but difficult to deliver (Penney & Wellard 2007). There has been notable growth in the active involvement of consumers at the macro level of health-care services, including consumer roles on boards of management, ethics committees and consumer reference groups. These activities are important and have had some impact on shifting the focus of health-care organisations to consumer needs rather than professional and institutional needs. Wider micro-level partnerships in care are less evident. A recent doctoral work of Penney (2005) identified the struggle of both nurses and older consumers to understand how partnerships in care can occur in the current organisation of health-care services where staff experience constraints in both time and space. The structures of health-care services position consumers with the identity of patient and consequently subject to a range of mechanisms associated with legal and risk management regulations.

Policy drivers: taking action

The global challenge is increasingly clear. There is a need for radical shifts in the way health is managed to address the impact of the epidemic of chronic illness. Clarity about preventable risk factors and optimal disease management provide clear direction for action in the prevention and control of chronic illnesses. The WHO (2005) has developed a detailed evidence-based action plan to assist countries in identifying potential strategies for reducing the burden of chronic illness, which needs to target both populations and individuals and recognise the social determinants of health. Taxation and price control, for example, could
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make alcohol and tobacco less affordable and provide subsidies to reduce the costs of healthy foods. Similarly, investing in improving the built environment in community-based projects could assist in providing accessible safe spaces for increased activity. These are preventative strategies. Additionally, WHO (2005) makes recommendations for the effective improvement of chronic disease management including the establishment and maintenance of effective clinical information systems, the provision of multidisciplinary health-care teams with an emphasis on primary health care and support for patient self-management programmes. While the arguments in support of these strategies are clear, the feasibility of implementation is more problematic. Implementation of taxation reform and prioritisation of infrastructure development, which lays emphasis on preventative health, are sensitive political issues and in all countries compete with other stakeholders who prioritise economic investment differently. Discussion of the complex socio-political landscape that influences the advancement of these strategies is beyond the scope of this chapter. However, the strategy for promoting patient self-management has received considerable attention and will now be explored.

Self-management has been increasingly adopted as part of health policy in a number of developed countries (e.g. in the UK policy ‘Expert Patient: A New Approach to Chronic Illness for the 21st Century’ [Fox 2005] and in Australia as part of the Chronic Disease Strategy [Dowrick 2006]). The idea of self-management programmes situates persons with chronic illness as central, with expertise and understanding of their illness and the ability (actual or potential) to assume responsibility of their management of their own health. Self-management programmes also assume some form of partnership between the individuals with the illness, the family, carers and health professionals. Self-management is most commonly conceived as involving:

... the individual with a chronic condition working in partnership with their carers and health professionals so that they can: know their condition and various treatment options; negotiate a plan of care; engage in activities that protect and promote health, monitor and manage symptoms and signs of illness, manage the impact of illness on physical functioning, emotions and interpersonal relationships.

(McDonald et al. 2004, p. 1 cited in Beckmann et al. 2007)

There are a number of different approaches to patient self-management, but the most widely adopted model internationally was developed by Kate Lorig and colleagues at Stanford University and based on a self-efficacy approach (Lorig & Holman 2003). The Stanford model uses a peer-led approach with a focus on sustained behavioural change. Advocates of this model have published evidence of demonstrated benefits using the widely accepted methods of randomised trials (Gifford et al. 1998; Lorig et al. 1999).

Self-management programmes also have critics. Concern has been raised about the focus self-management programmes place on individuals which ignores, or marginalises, the broader social and economic context that influences illness