Self-Management in Chronic Illness

Principles, Practice, and Empowerment Strategies for Better Health

Jose Frantz
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Editors
Jose Frantz
University of the Western Cape
Bellville
South Africa

Anthea Rhoda
Department of Physiotherapy
University of the Western Cape
Cape Town
South Africa

Laura Schopp
Department of Health Psychology
University of Missouri
Columbia, MO
USA

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Preface

Self-Management: An Empowering Strategy for Health

The editors identified self-management as a key component of the management of health. In reflecting on self-management, it is important to note that it would be difficult for individuals not to be aware of their specific health behaviours, which could include unhealthy behaviours. This book aims to provide insights into the aspect of self-management as it relates to its definition and application. It is intended to highlight how self-management can be applied to various long-term health conditions, for different populations or target groups and in different contexts. Academics will be able to use the book to engage postgraduate as well as undergraduate students in understanding self-management as a technique that can be used by individuals living with long-term conditions to facilitate community reintegration. It can also be used by clinicians to enhance their management of individuals with long-term conditions. Furthermore, researchers could use the text to expand and support their research in this area. The book consists of three main parts. Part one provides an overview of self-management and the rationale for its application, while part two presents the applications of self-management in specific clinical conditions and part three illustrates its use in different sub-populations or target groups.

The authors for each chapter were selected based on their areas of expertise. The editors Professors Frantz and Rhoda are from the University of the Western Cape, Cape Town, South Africa, and Professor Schopp is from the University of Missouri, Columbia, Missouri, USA.

Bellville, South Africa — Jose Frantz
Columbia, MO, USA — Laura Schopp
Cape Town, South Africa — Anthea Rhoda

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Contributors

Reham Altigani Department of Physiotherapy, University of the Western Cape, Cape Town, South Africa

Seyi Ladele Amosun University of the Western Cape, Cape Town, South Africa

Brook Clark University of Missouri, Department of Health Psychology, Columbia, MO, USA

Stephanie Clookey University of Missouri, Columbia, MO, USA

David Moulaee Conradsson Department of Neurobiology, Care Sciences and Society, División of Physiotherapy, Karolinska Institute, Stockholm, Sweden

David M. DeJoy Workplace Health Group, College of Public Health, University of Georgia, Athens, GA, USA

Ina Diener University of Stellenbosch, Stellenbosch, South Africa

Jose Frantz University of the Western Cape, Bellville, South Africa

Ryan Groenewald Department of Physiotherapy, University of the Western Cape, Cape Town, South Africa

Levona J. Johnson University of the Western Cape, Bellville, South Africa

Fiona Jones Centre for Health and Social Care Research, St Georges University of London and Kingston University, London, UK

Conran Joseph Department of Health and Rehabilitation Sciences, Division of Physiotherapy, Stellenbosch University, Cape Town, South Africa

Wilson Majee Department of Health Sciences and Public Health, University of Missouri, Columbia, MO, USA

Department of Occupational Therapy, Faculty of Community & Health Sciences, University of the Western Cape, Cape Town, South Africa

Janene E. Marais University of the Western Cape, Bellville, South Africa

Zamantungwa N. Mvelase University of the Western Cape, Bellville, South Africa

Eugene Nizeyimana Department of Physiotherapy, University of the Western Cape, Cape Town, South Africa

Heather M. Padilla Workplace Health Group, College of Public Health, University of Georgia, Athens, GA, USA

Thandi Puoane School of Public Health, University of the Western Cape, Bellville, South Africa

Anthea Rhoda Department of Physiotherapy, University of the Western Cape, Cape Town, South Africa

Laura Schopp University of Missouri, Department of Health Psychology, Columbia, MO, USA

Matthew L. Smith Center for Population Health and Aging and Department of Environmental and Occupational Health, School of Public Health, Texas A&M University, College Station, TX, USA

Lungiswa Tsolekile School of Public Health, University of the Western Cape, Bellville, South Africa

Lisa Wegner Department of Occupational Therapy, Faculty of Community & Health Sciences, University of the Western Cape, Cape Town, South Africa

Mark G. Wilson Workplace Health Group, College of Public Health, University of Georgia, Athens, GA, USA

Part I
Understanding Self-Management

Chapter 1
Overview of Self-Management

Jose Frantz and Anthea Rhoda

Overview

This book aims to orientate the reader to the importance of self-management and how it has been used in different contexts. Self-management is a term that was used as early as the 1960s, where it was applied during the rehabilitation of chronically ill children. As self-management has evolved, essential skills identified include behavioral modeling, decision- making, planning, social persuasion, locating, accessing and utilizing resources, assisting individuals to form partnerships with their health care providers, and taking action [1]. These are important skills that would benefit health professional educators, clinicians, and patients.

This book aims to provide insights into self-management as it relates to its definition and application. It is intended to highlight how self-management can be applied to various long-term health conditions, for different populations or target groups and in different contexts. Academics will be able to use the book as a textbook when teaching postgraduate and undergraduate students about self-management as a technique that can be used by individuals living with long-term conditions to facilitate community reintegration. It can also be used by clinicians to enhance their management of individuals with long-term conditions. Furthermore, researchers could use the text to expand and support their research in this area.

Part One provides an overview of the book and the rationale for self-management.

Part Two presents the application of self-management in specific clinical conditions. Chronic long-term health conditions affect sufferers in a way that decreases

J. Frantz (✉)
University of the Western Cape, Bellville, South Africa
e-mail: jfrantz@uwc.ac.za

A. Rhoda
Department of Physiotherapy, University of the Western Cape, Cape Town, South Africa
e-mail: arhoda@uwc.ac.za

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functional ability, which in turn affects the ability to function optimally within the physical, environmental, and social environment [2]. The illustrative clinical conditions included in Part Two are stroke, spinal injuries, low back pain, and diabetes. The chapters present an overview of the specific condition including the clinical picture and impact of the condition. The Chap. 5 which focuses on stroke presents the Bridges Self-Management Program as an example of a self-management support program designed to manage outcomes post-stroke. The Chap. 6 on low back pain and self-management discusses various evidence-based management techniques to address chronic low back pain and a discussion of the GLA:D self-management support program for chronic low back pain. In their discussion about self-management in spinal cord injuries, the authors highlight the importance of theory and the Health Action Process Approach model, as well as the facilitators and barriers that could occur when implementing self-management in patients with spinal cord injuries in Chap. 3. The Chap. 4 on self-management and diabetes reflects on personal patient empowerment through the Diabetes Self-Management Education and Diabetes Self-Management support.

Part Three illustrates how self-management can be used in different population groups and settings. In accordance with Ritchie's (2019) three main functional age categories (children younger than age 14, elderly over age 65, and working age from 25 to 65 years), we examine self-management among youth, the elderly, and those in the workplace [3]. The chapter on self-management for youth highlights the importance of active leisure and its role in promoting self-management skills among rural youth in particular.

This text also describes the high prevalence of multimorbidity and the importance of self-management for non-communicable diseases among the elderly. The author emphasizes the importance of a collaborative approach to supporting healthy choices and healthy behaviors.

The chapter focusing on self-management in the workplace examines the needs of working-aged adults between 16 and 64 years and investigates the workplace as an important setting to reach individuals with health-related support. This chapter highlights the importance of self-management programs to combat and effectively assist in managing the clinical and financial impacts of chronic disease in the working-age population.

We also realize that intervention is not only needed in institutions such as hospitals or workplaces but also needed in our communities. Thus, the chapter on the community health workers and the role they can play in promoting self-management interventions is essential. Community health workers have been identified as an important cadre of health professionals that can assist in meeting the health needs of society.

Finally, it is important to investigate the role of self-management strategies in the fitness industry, with its focus on modifiable factors linked to nutrition and physical activity. The fitness industry plays a key role in sharing the message linked to health promotion and education. This chapter describes the context of fitness facilities, explains the rationale for self-management in the industry, and assists fitness professionals to facilitate improved health behaviors.

Chapter 1: Overview of the chapters

The impact of disease on the health of individuals across all ages will continue to grow. As we contemplate the management of disease and individuals' health, we need to consider interventions that will slow the impact. The active engagement of the individual, so central to self-management, is key to addressing physical, mental, emotional, and spiritual health. This chapter addresses ways in which self-management can assist individuals to manage their health and how self-management can be effectively be used in diverse sectors at many levels of acuity.

Chapter 2: The Case for Self-Management

Self-management of chronic conditions is among the leading candidate solutions for high-need, low-resource health care environments. This chapter will describe the breadth of chronic conditions that have proven amenable to a self-management approach and define self-management approaches that have been used broadly in chronic condition management worldwide. The chapter provides a brief history of self-management as a conceptual approach and describes an array of self-management approaches that have garnered empirical support. Self-management has proven effective as a primary prevention strategy, as well as for secondary and tertiary prevention among strikingly diverse physical and mental health conditions. Self-management as a core intervention strategy is robust to condition, age, and demographic factors, is cost-effective, amenable to tailoring, is relatively easy to implement in a range of settings, and can be delivered by lay leaders. As the burgeoning body of research support continues to grow on this highly effective condition management approach, public health systems would do well to adopt self-management as a key systematic intervention strategy.

Chapter 3: Self-Management and Spinal Cord Injuries

Spinal cord injury (SCI) almost always results in a decrement in functioning over the lifespan. With the lack of specialized SCI services in low- to middle-income countries and the trend of shorter stays in rehabilitation facilities following SCI, a definite need exists to empower clients to manage themselves, often while they await critical services or as they attempt to expand their functioning frameworks. Self-management (SM) is now a common term used in many health promotion and patient education intervention programs designed to help individuals manage their symptoms, treatment, physical and psychological consequences, and lifestyle changes inherent in living with a chronic condition such as SCI. This chapter aims

(1) to describe spinal cord injury and its consequences, (2) to identify self-management intervention programs and associated skills as well their effectiveness on SCI outcomes, and (3) to highlight the need of integrating self-management programs into existing health systems in resource-constrained settings. Goal setting, action planning, problem-solving, decision-making, coping strategies, and resource utilization are critical tools in SCI self-management. Although the self-management interventions identified seemed to be cost-effective, the use of self-management in low- to middle-income countries is limited, indicating that self-management is not yet fully included in health care systems despite the evidence of its empirical support and potential utility. Therefore, there is a need to advocate the adoption or contextualization of promising available self-management programs into existing health systems in resource-constrained settings.

Chapter 4: Self-Management and Diabetes

Diabetes mellitus is a major contributor to the global burden of non-communicable disease. Evidence-based treatment guidelines for the management of diabetes have been widely distributed. Still, there are several challenges in their implementation both for health personnel and patients, especially in low- and middle-income countries (LMIC), where health facilities are overburdened with infectious disease coupled with an increasing prevalence of non-communicable diseases. The World Health Organization has recognized the importance of patients' active involvement in managing their diabetes to enable them to take control of their condition, prevent complications, and improve quality of life. This chapter describes self-management in diabetes, including theories and models and empowerment approaches such as the diabetes self-management education and self-management support. Facilitators and barriers to diabetes self-management are described, followed by policies relevant to diabetes self-management. This chapter also highlights the self-management interventions that have been implemented in developed countries and how low- and middle-income countries can adopt, adapt, and learn from these interventions.

Chapter 5: Self-Management and Stroke

Stroke continues to be a major cause of death and disability across the globe. Stroke impacts the physical, psychological, and quality of life, and effective stroke interventions should thus be holistic and multi-dimensional. In addition to focusing on stroke recovery, self-management interventions targeting coping strategies are critical. In addition to reviewing the impact of stroke on individuals, this chapter presents as an example the Bridges Self-Management Program developed for the stroke population. The authors provide information about contextualization of the Bridges Self-Management Program, as well as recommendations for future directions on stroke clinical practice.

Chapter 6: Self-Management and Low Back Pain

Low back pain is a leading cause of musculoskeletal disability worldwide, recorded in both low- and high-income countries. Recent levels of disability associated with low back pain have increased despite a significant increase in expenditure on low back pain management. Effective care for persistent musculoskeletal pain is informed by triage to rule out red flags, identification of pain mechanisms and applicable evidence-based interventions. Currently, research on low back pain encourages exercise rehabilitation and pain education, both of which allow for self-management. The person-centered care and shared decision-making of the self-management model can support adherence to prescribed exercise regimens and may lower healthcare utilization. Clinicians have a collective responsibility to educate patients, the community, funders, policymakers, and other clinicians on self-management to help reduce the disability and cost burden in society. Although the current evidence for self-management as a treatment approach in low back pain is just beginning to evolve, contemporary knowledge of pain neuroscience and a move toward patient-centered care may demonstrate improved outcomes in the future.

Chapter 7: Self-Management in the Youth

Youth have the potential to play a major role in society as contributing citizens and change agents. However, many youths face a multitude of challenges such as obtaining post-school education and gainful employment. These challenges can negatively influence youth's capacity and skills to manage themselves and lead to their disengagement from society. Youths who are disengaged or marginalized from engaging in the typical roles and activities expected during young adulthood are vulnerable. Vulnerable youth, for example, might live in low socioeconomic, disorganized, or rural contexts, or they might be involved in risk behaviors such as substance use or gangs. Given the emerging global youth disengagement epidemic, and anticipated population growth, there is a growing need for programs that enable youth to acquire the capacity and skills for self-management in order to equip them to prevent and manage health challenges.

Chapter 8: Self-Management in the Elderly

Population aging is considered to be a success of the twenty-first century. The World Health Organization (WHO) developed a global active aging policy framework in 2002, defined as "the process of optimizing opportunities for health, participation and security, in order to enhance quality of life and wellbeing as people age." The number of persons aged 60 years and older will be approximately 1402 billion in 2030 and 2092 billion in 2050. This incremental trend raises public health

challenges, including chronic non-communicable diseases projected by the WHO to account for 60% of morbidity and disability by 2020. Multimorbidity is prevalent among elderly persons, and the leading contributors include cardiovascular diseases, chronic respiratory diseases, musculoskeletal diseases, and neurological and mental disorders, and the self-management model is both adaptable and robust enough to be useful in managing highly varied and complex comorbidities. As a system that can flexibly support active aging, self-management is conceptualized in community-based non-residential day centers for elderly persons.

Chapter 9: Community Health Workers as Key Contributors to Self-Management Programs

Primary health care settings play a vital role in community disease prevention and health promotion. Self-management has been identified as a key tool that can be used to combat the increased prevalence of non-communicable and chronic diseases. A key driver of the interest in self-management is the potential to make a significant contribution to *efficient* health care delivery. As we focus on a patient-centered approach to health care, it becomes important to shift some of the care to the patient, and community health workers are an important cadre of health professionals who can support patient self-care. This chapter investigates the role that community health care workers can play in driving the agenda of self-management in community settings, with a focus on context (psychological impact of Community Health Workers (CHWs) in performing their duty), conditions (legal considerations in using CHWs as frontline workers), and performance (benefits of health sectors using community health workers to promote self-management interventions). The chapter concludes with a discussion of factors to consider when engaging communities with self-management approaches.

Chapter 10: Self-Management in the Workplace

Chronic diseases are multi-dimensional and affect numerous aspects of people's lives, including work. Depending on the chronic condition(s) involved, between 22% and 49% of employees experience difficulties meeting physical work demands and between 27% and 58% report that they have problems meeting psychosocial work requirements. Work organizations are acutely aware of this issue and the impact of unmanaged chronic conditions on productivity and costs. For employees of 18–64 years with fewer than four conditions, the average annual healthcare claims have increased by $1700 to $2000 per person for each additional chronic condition. Given that the chronic disease management efforts may have the largest impact on employers' healthcare costs, and in light of the aging workforce, it is

clear why organizations are making self-management programs an important part of their workplace health promotion efforts. This chapter reviews the extent of and the rationale for self-management in the workplace. It describes the workplace context, how it differs from other settings, and how self-management fits into workplace programs. The chapter highlights legal and ethical issues and presents case descriptions of self-management programs conducted in workplaces. The chapter concludes by offering future directions for self-management programs in the workplace.

Chapter 11: Self-Management in Nutrition and Exercise

Chronic disease is a burden to patients and healthcare systems around the world, compromising patient welfare and creating exorbitant costs. Lifestyle interventions such as appropriate nutrition and exercise can effectively prevent, manage, and cure various chronic diseases. However, patients struggle to incorporate proper nutrition and exercise regimens in their daily lives; one in four adults do not meet the World Health Organization's physical activity guidelines, and global rates of obesity have tripled in the past 30 years. As a result, rates of chronic disease and related complications are on the rise. Simultaneously, the fitness industry has experienced paralleled growth. The global expansion of health clubs and gyms has produced 50% growth in revenue over the last decade. In 2018, the Global Wellness Institute estimated the physical activity economy to be worth 828 billion US dollars, with projections for continued growth. Nutrition and exercise professionals are becoming liaisons between formal healthcare recommendations and patients in need of lifestyle interventions. This chapter will describe the context of fitness facilities, explain the rationale for self-management in the industry, and assist fitness professionals to facilitate improved health behaviors.

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Chapter 2
The Case for Self-Management

Brook Clark and Laura Schopp

Introduction

The World Health Organization defines non-communicable or chronic diseases as conditions that are of long duration, progress slowly, and are the result of a combination of genetic, physiological, environmental, and behavioral factors [1]. Chronic diseases kill 41 million people each year, equivalent to nearly three-quarters (71%) of all deaths globally. Data show that people of all age groups, regions, and countries are affected by chronic diseases, and each year 15 million people between the ages of 30 and 69 years die from a chronic disease. Referred to as premature deaths, these fatalities disproportionately occur in low- and middle-income countries (LMIC) (85%) with devastating effects on the socioeconomic fabric of communities [1]. The World Health Organization has identified four main groups of diseases that account for over 80% of all premature deaths due to chronic illness [1]. These deaths include (1) cardiovascular diseases such as heart attack and stroke (17.9 million/year), (2) cancers (9 million/year), (3) respiratory diseases such as asthma and chronic obstructive pulmonary disease (3.9 million/year), and (4) diabetes (1.6 million/year) [1]. It is not unusual for individuals to be diagnosed with more than one chronic condition. For example, in the United States, six in ten adults have one chronic disease and four in ten adults have two or more chronic diseases [2], with numbers continuing to grow.

Risk factors for chronic diseases have been well established in the literature. While genetic, environmental, and economic factors undoubtedly influence whether an individual will acquire a chronic disease, other common, behavioral risk factors cut across all other factors and have been shown to cause the majority of chronic illness worldwide [1]. Examples of behavioral risk factors include an unhealthy diet

B. Clark · L. Schopp (✉)
University of Missouri, Department of Health Psychology, Columbia, MO, USA
e-mail: schoppl@health.missouri.edu

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(often focused on convenience over nutrition), lack of regular physical activity, and tobacco and other substance use. Fortunately, behavioral risk factors are modifiable and research has clearly demonstrated that lifestyle changes are possible, achievable, and effective in improving health. Nonetheless, many patients are not sufficiently equipped with the tools, resources, skills, and abilities that are necessary to make and maintain significant behavioral change. Chronic disease self-management, or the process by which patients actively collaborate with healthcare professionals around health-related goals, is one approach that has been shown to be effective in improving health outcomes for individuals with chronic conditions.

The body of literature that focuses on self-management strategies has grown greatly in breadth and depth since its origins in the 1960s and 1970s. Since then, core principles of self-management have been applied to an increasing number of conditions and populations, often with favorable outcomes. This chapter will give an overview of the conceptual and pragmatic definitions of "self-management," and will review several examples of commonly utilized self-management models. Then, individual research that illustrates specific advantages of self-management will be presented. These advantages include the effectiveness of self-management across the prevention spectrum, its application across clinically and demographically diverse populations, and its cost effectiveness, making it an important resource for health promotion or health improvement in low-resource environments and low- to middle-income countries. Finally, limitations and special considerations will be discussed.

Self-Management Definition

Conceptual Definition

Origins of the term "self-management" are associated with Thomas Creer and colleagues [3, 4], who first used the term in their work examining the management of chronic illness in children [3, 4]. Influenced by the work of Albert Bandura [5], Creer and colleagues [3, 4] proposed that individuals bear responsibility for, and are capable of, proactively managing their own conditions. Whereas models of healthcare at the time emphasized the expertise of the healthcare professional, Creer and colleagues [3, 4] emphasized the central role of patients in managing their own conditions through active problem-solving and self-tailoring [4]. However, they also understood that self-management behaviors would not likely occur without confidence in one's ability to make and maintain change. Bandura's [5] theory of self-efficacy provided a possible explanation as to the mechanisms by which self-management achieves its success. According to Bandura [5], self-efficacy develops through experiences of mastery, vicarious experiences, social persuasion, and physiological states. Put simply, the act of "doing" facilitates self-confidence, which begets further engagement, which ultimately results in increased self-efficacy. In the context of chronic conditions, self-efficacy is the currency of self-management.

Self-efficacy empowers individuals to cope with all that a chronic condition entails, including symptom management, treatment considerations, and lifestyle changes, as well as the physical, social, and emotional consequences of living with a chronic condition [5].

Practical Definition

Broadly speaking, self-management may be defined as "the day-to-day management of chronic conditions by individuals over the course of an illness" [6 p26]. Interestingly, this definition does not include qualifiers about the extent to which a person proactively and healthfully self-manages. This fact was insightfully pointed out by Lorig and Holman [7], who said, "One cannot *not* manage." Consequently, the question of interest becomes not *if* one manages, but *how* one manages [7, 8]. What is it then, that differs between individuals and that results in some patients coping more successfully than their demographically similar counterparts with the same chronic condition? What are the essential, concrete tasks of effective self-management?

It is not uncommon for patient education programs aimed at increasing wellness to focus their efforts on tasks such as adhering to a medication regimen and eating a nutritious diet. While undoubtedly important, the "work" of chronic illness self-management as outlined by Corbin and Strauss [9, 10] involves a set of three essential tasks: medical management, behavioral management, and emotional management. Medical management involves such tasks as adhering to a medication regimen and attending medical appointments, whereas behavioral management refers to modifying lifestyle choices (e.g., decreasing sodium intake) and adapting to new life roles (e.g., accepting assistance from others). Emotional management includes coping with feelings and emotions related to dealing with a long-term, or lifetime, condition (e.g., coping with depression, anxiety, fear). Corbin and Strauss [9] recognized that for individuals to effectively manage their chronic conditions, all three tasks must be integrated into any self-management approach.

Lorig and Holman [7] further developed the tasks of self-management to include five core self-management skills: problem-solving, decision-making, resource utilization, partnerships with providers, and acting. The authors note that because self-management deals directly with problems, problem-solving must be a fundamental component. They characterize problem-solving as the ability to identify a problem or problems (from the patient's own perspective), generate possible solutions, implement solutions, and evaluate the results [7]. Decision-making is the second core self-management skill and involves the daily decisions individuals make in response to living with a chronic condition. Optimal decision-making requires that individuals have a basic understanding of their chronic condition and how decisions may impact wellness in the short term and in the long term. For example, it is not uncommon for patients with chronic pain to avoid activity as a strategy for decreasing pain. While this may seem like a sensible approach, inactivity often leads to