Self-Management in Chronic Illness

Principles, Practice, and Empowerment Strategies for Better Health

Jose Frantz
Laura Schopp
Anthea Rhoda
Editors

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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.

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Columbia, MO, USA — Laura Schopp
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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

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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

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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 greater levels of pain through deconditioning and mood changes associated with inactivity. Thus, it is critically important that patients have sufficient information about their condition, and guidelines to follow, in order to make the best decisions they can on any given day. The third core self-management skill consists of finding and utilizing resources for additional support, such as how to find assistance with prescription costs, the best kind of shoes for exercise, or how to connect with a support group. Often overlooked, this skill involves directly showing people where and how to access resources for themselves. Newfound skills in this area may also boost feelings of self-efficacy, the axle around which all other skills turn. The fourth self-management skill, according to Lorig and Holman [7], is helping individuals form collaborative and supportive alliances with their healthcare providers. Traditional models of healthcare emphasize health professionals as the experts with solutions and patients as passive consumers of this information. Self-management acknowledges that while health professionals are the experts in medicine, patients are the experts in their own lives [8]. Bodenheimer and colleagues argue that patients may be more committed and engaged in ongoing care when the responsibility for decision-making is shared, which may ultimately lead to improved clinical outcomes. The last core skill involves taking action and this is accomplished by goal-setting and initiating new behaviors. Goal setting in self-management involves patients making SMART goals (specific, measurable, attainable, relevant, and time-bound) [11]. Providers should follow up with patients on progress toward goals and anticipating obstacles.

A multitude of self-management models exist in the literature, each with its own elements, aims, strengths, and limitations. The models listed below have been selected for discussion because they have been subjected to testing across a variety of settings, populations, and conditions, and have evidenced improvements in the health status of the participants involved. They are provided as examples of different approaches to self-management; however, many other models have shown encouraging results and warrant further investigation. For a more comprehensive examination of self-management models, the following reviews may be considered [12–14]. In addition, Mills et al. [15] offer international consensus guidelines for self-management groups.

Common Models of Self-Management

Stanford Model

Perhaps the most widely researched and utilized model, the Chronic Disease Self-Management Program (CDSMP) led by Kate Lorig of Stanford University leverages behavioral change by way of increased self-efficacy in patients [16–18]. This model descends from the theoretical framework first put forth by Albert Bandura [5] in which expectations of personal mastery have a direct effect on whether coping behaviors are initiated and maintained. Thus, patients learn and practice skills that build confidence and self-efficacy. The CDSMP model is an evidence-based, peer-led self-management education course that can be administered to individuals across diverse chronic conditions. The course typically involves 10–15 participants who meet in a group over the course of 6 weeks. Several underlying assumptions of the CDSMP model are that (1) different chronic conditions are united by similar experiences, challenges, and tasks; (2) patients can successfully learn to manage chronic conditions on a day-to-day basis; and (3) that the practice of self-management strategies will improve health status and decrease reliance on health care resources [16, 19, 20]. There are numerous advantages to CDSMP, with one primary advantage related to group leadership [18]. The CDSMP course is peer-led by individuals with chronic conditions themselves, thus potentially increasing the credibility of course content while also facilitating self-efficacy through group work and peer-to-peer sharing. The idea of peer leadership has been supported by the work of Cameron and colleagues [21], who demonstrated that identification with other program members and peer leaders produced group-derived efficacy, from which individual self-efficacy could then be harnessed. This approach may be considered less threatening than other models, in which groups are led by medical personnel and/or others in perceived positions of authority. Other advantages include the incorporation of pre- and post-assessments to facilitate objective measurement of behavioral change and program success. Primary disadvantages to the CDSMP model include concerns about confidentiality in group settings, differing levels of comfort with social interactions, and limitations around group involvement (i.e., groups are time-limited and not intended as long-term support [14]), as well as challenges related to extensive group leader training and the logistical challenges of 2–3 hour weekly in-person meetings.

5 A’s Model

Originally developed in the United States as an intervention for smoking, the 5 A’s model is an evidence-based approach frequently utilized in primary care settings as a method of fostering communication between patients and health care professionals to promote behavioral change across a broad range of health conditions [22–27]. The 5 A’s model is based upon principles of motivational interviewing in which readiness for change is explored through a shared dialogue. The 5 A’s model has been found to be effective in facilitating behavioral changes such as smoking cessation [27], dietary change [28], and weight loss in obesity [29]. Specifically, the 5 A’s are as follows: (1) “Assess” (ask the patient about the behavior of interest and assess for readiness to change), (2) “Advise” (offer a clinical management plan), (3) “Agree” (set collaborative, agreed-upon goals), (4) “Assist” (assist patients in identifying motivators and barriers to meeting goals), and (5) “Arrange” (schedule follow-up appointments and make referrals to additional resources). Adaptations of the 5 A’s model exist in the literature, with significant overlap [30–34]. Advantages of this approach are that it is straightforward, it uses an acronym for easy recall, it acknowledges patients as their own experts, it conforms to patients’ existing expectations about healthcare delivery (patients expect to receive support, advice, and recommendations), and it can be applied to multiple chronic conditions with positive outcomes. Additionally, the 5 A's model is designed to be brief (5–10 minutes) and can be incorporated into fast-paced clinic settings more easily than interventions that require additional, outside meetings or groups. Disadvantages of the 5 A's model are that it may not be well suited for patients with complex psychosocial concerns (e.g., brevity may be disadvantageous); it requires flexibility and commitment on the part of the medical professional to ensure that interactions are patient-centered (e.g., there is no formalized, organizational oversight); and evaluation of outcomes is largely dependent on patients' reports/feedback and providers' clinical judgment [35].

Chronic Care Model

The Chronic Care Model (CCM) proposes that the global prevalence of chronic disease will not diminish without a sweeping shift away from acute, reactive models of healthcare toward proactive, integrated, patient-centered models of healthcare [13, 20, 34]. The CCM is evidence-based and consists of six major elements that interact to promote high-quality care for patients with diverse chronic diseases. The six elements are (1) "health system" (the organization seeking to promote high-quality care), (2) "delivery system design" (includes how services are organized and delivered), (3) "decision support" (guidelines for care that are consistent with scientific evidence and patient preferences), (4) "clinical information systems" (involves an organized system of patient and population data to promote efficient exchange of information with patients), (5) "self-management support" (emphasizes the patient's primary role in managing their health and incorporates strategies such as goal-setting, assessment, action-planning, and problem-solving), and (6) "community" (encourages partnerships with community stakeholders such as senior centers or local health and wellness organizations, and advocates for policies that improve patient care and general quality of life) [36]. Taken together, these elements nurture productive interactions between knowledgeable, motivated patients and efficient, proactive health care teams. As they are highly compatible, the elements of the 5 A's model listed earlier (Assess, Advise, Agree, Assist, and Arrange) are frequently incorporated into the larger conceptual framework of the CCM. This consolidation strategy offers the ease associated with implementing the 5 A's model, while also providing the organizational-level structure of the CCM, including routine assessment and feedback. Advantages of the CCM are similar to those observed in the 5 A's model and include excellent fit and utility within a primary care context, acknowledgment of the patient as expert, use of a team approach that includes other professionals and community organizations (instead of depending solely on individual providers as in the 5 A's model), and a system of delivery that facilitates enhanced program assessment. Disadvantages include that the model requires a broad transformation in the way providers and patients think about healthcare and healthcare delivery. Thus, it may be less easily and quickly implemented. The model may also be somewhat cumbersome due to its numerous components, potentially leading to a lack of cohesion if not executed in an engaged, collaborative, and consistent manner.

Flinders Chronic Condition Management Program (Flinders Program)

Led by Malcolm Battersby, Flinders University developed the Flinders Program in the mid- to late-1990s in response to the increasing incidence and prevalence of chronic conditions among both minority and majority cultures in Australia [37]. The Flinders Program (FP) utilizes a generic set of tools and techniques to more effectively partner with patients around self-management of chronic conditions. The FP aligns well with the CCM in that it integrates similar fundamental elements such as collaboration, goal-setting, development of an individualized care plan, and follow-up/monitoring [34]. Like the CCM and CDSMP, the FP endorses the idea of commonality among conditions and tasks are intended for use with diverse conditions and populations [37, 38]. The FP comprises seven principles of self-management including (1) "Knowledge" (patients have an understanding of their condition), (2) "Involvement" (patients actively share in decision-making), (3) "Care Plan" (patients follow the plan they create with health professionals), (4) "Monitor and Respond" (patients monitor and manage symptoms), (5)"Impact" (patients manage the impact of their condition on their physical, emotional, and social life), (6) "Lifestyle" (patients adopt lifestyles that promote health), and (7) "Support Services" (patients explore and utilize support services) [38]. A number of validated questionnaires specifically developed for the FP are integrated into the approach, including the Partners in Health Scale [39] which includes 12 items that ask patients to rate their knowledge and ability to monitor and manage their condition and the Cue and Response Interview which utilizes motivational interviewing techniques to further explore patients' responses to the Partners in Health Scale. Both the health professional and the patient score the patient's responses and these are compared as a method for increasing and deepening dialogue. The Problems and Goals Statement [39] is another assessment tool that helps to clarify differences in how professionals and patients may view the patient's main problem and helps the patient identify goals to work toward. Ultimately, the information gathered through interviews and questionnaires is integrated into a personalized care plan which includes scheduling for review of the plan and progress toward goals in the future. Advantages of the Flinders Program include its structured format that targets patients' identified problems and goals (as opposed to professionals' identified goals), its applicability to a wide range of conditions and contexts, its incorporation of assessment tools, and its flexibility (e.g., use of either or both interview and questionnaires to create an individualized care plan for each patient).

The above overview of commonly utilized, self-management models (CDSMP, 5 A's, CCM, and FP) is intended to provide the reader with a general sense of individual models' components, strengths and limitations, and the areas in which they intersect. For the remainder of this chapter, several advantages of the use of self-management models will be discussed. These include the following: self-management models are effective across the prevention spectrum, they are robust (e.g., they are effective across clinically and demographically diverse populations), and they are relatively of low cost. For the reader's ease, the aforementioned advantages will be described in sections and illustrated with individual studies.

Advantages of Self-Management

Effective Across the Prevention Spectrum

Primary Prevention

Primary prevention aims to prevent disease before it occurs. Primary prevention strategies include preventing exposures to risks that can lead to disease, changing behaviors that lead to disease, and increasing resistance to disease if risks are present [40].

Disability in Frail Older Adults

This randomized controlled trial evaluated the impact of a 1-year, community-based, partnership with primary care providers to improve self-management and disability prevention in frail older people aged 70 and above [41]. Objectives examined healthcare utilization among participants, including inpatient hospitalizations and use of psychoactive medications. Leveille and colleagues [41] based their intervention in community senior centers as a strategy for reaching more individuals in an environment in which they already gather, while also being cost-effective. Primary care providers referred individuals to the program who were receiving treatment for at least one chronic condition. Patients with dementia and terminal illness were excluded. Prior to intervention, participants completed a variety of questionnaires about aspects of health and functional status. Physical assessments included measures of mobility, gait, and strength. Repeat assessment occurred at the 6 month and 1-year marks. The program was led by a geriatric nurse practitioner (GNP) and focused on two principal targets: physical activity and self-management. Assorted physical activities were offered through the senior center such as swimming, walking, dancing, and strength training. Home exercise options were offered for those who wished to exercise in their homes. The primary intervention included two components: (1) individual counseling and (2) group classes. The GNP provided individual counseling in self-management in which a plan was created based on patient-identified goals as well as goals offered by the primary care provider. Participants attended weekly 2-hour classes conducted by trained lay leaders. Called Chronic Illness Self-Management, the group offered peer support, health information, and discussion of disease self-management principles. Individuals randomized to the control group did not meet with the GNP, but instead received a tour of the senior center and a schedule of all the activities offered at the senior center. Assessment occurred at 6 and 12 months. Results revealed significant between-groups differences (in the expected directions) in levels of physical activity, senior center participation, and use of psychoactive medications. Notably, the number of hospitalized participants increased by 69% among the control group and decreased by 38% among the intervention group. In addition, the total number of inpatient hospital days was significantly lower in the intervention group than in the control group ($M = 33$ days vs. $M = 116$ days). Findings demonstrated that a community-based, self-management approach was effective in preventing disability and decreasing hospitalizations in this sample of older adults with chronic conditions.

Secondary Prevention

Secondary prevention aims to reduce the impact of a disease that has already occurred through early detection and treatment, promotion of strategies to prevent recurrence, and implementation of programs aimed at returning individuals to their highest levels of functioning [40].

Stroke

Evans-Hudnall and Stanley [42] conducted a randomized, clinical trial of a pilot intervention aimed at improving secondary stroke care among minority individuals. Specific aims were to improve stroke knowledge; compare the effects of the intervention (versus usual care) on health behaviors including diet choices, physical activity, and medication adherence; and examine the role of anxiety and depression on health-behavior outcomes. African-American and Hispanic participants of low socioeconomic status were recruited from the stroke intensive care unit of a large hospital in Houston, Texas. Participants were randomized to intervention and usual care groups. Those in the intervention group participated in the Secondary Stroke Prevention (STOP) program. The STOP program consists of three, 30- to 45-minute stroke self-care sessions, goal-setting activities, and an informational guide. Self-care sessions were provided by a health educator with a bachelor's degree and several years of experience facilitating self-care groups. Intervention components included problem-solving, goal-setting, and self-monitoring as well as stress management and relapse prevention. Sessions were offered at no cost and via telephone, and sessions offered support and guidance around accessing community resources (e.g., free smoking cessation assistance). Assessments occurred at baseline and at 4-week follow-up and measured health behavior and affective symptoms. Analyses demonstrated significant between-groups differences in terms of knowledge about stroke and knowledge about the effects of tobacco and alcohol on health. Results provided evidence that brief, secondary self-care treatment, via telephone sessions, was able to decrease risk factors in this sample of minority stroke patients [42].

Tertiary Prevention

Tertiary prevention aims to lessen the impact of an ongoing disease by helping individuals manage long-term, complex diseases to improve their ability to function and to improve quality of life [40].

Serious Mental Illness

Druss et al. [43] adapted Stanford University's Chronic Disease Self-Management Program (CDSMP) to improve medical self-management outcomes in individuals with serious mental illness (SMI). Called the Health and Recovery Peer (HARP) Program, this intervention utilized the core structure of the CDSMP, with adaptations including simplification of the CDSMP manual to a sixth-grade reading level and the inclusion of a self-management tracking tool for participants to record important information such as appointments, medications, physical activity, and nutrition. One unique aspect of HARP is the integration of paired participants who worked together to create action plans and achieve goals. Druss et al. [43] anticipated that pairing participants would facilitate motivation and provide added support and connection.

Adults aged 18 and older with serious mental illness were randomly assigned to treatment or usual care groups. Pre-intervention measures assessed patient activation (participants' perceived ability to manage his or her illness and health behaviors); aspects of disease self-management such as physical activity, use of health services, and medication adherence; and health-related quality of life. The intervention occurred at a community mental health center and involved six, peer-led sessions focused on basic concepts of self-management, exercise, management of pain and fatigue, nutrition on a limited budget, medication management, and working with a regular doctor. Those in the usual care group did not attend intervention sessions but continued with all routine medical and mental health services. Peer leaders assisted participants in the development of short-term action plans and modeled examples of effective interactions with providers. Action plans were created by participants, problem-focused, and included ideas for how to solve the identified problem. Post-intervention assessments on patient activation, self-management, and health-related quality of life were administered at the 6-month follow-up appointment. Results revealed significant differences between the groups in patient activation, with the intervention group showing significantly greater improvement than the usual-care controls. Results also demonstrated that the intervention group showed improvement in physical activity, medication adherence, and health-related quality of life. Findings add to the literature by demonstrating that slight adaptations to commonly used self-management models can facilitate improved health outcomes in populations that face additional barriers to wellness [43].

Robust

Clinically and Demographically Diverse Populations

A vast literature now exists that demonstrates the ability of self-management programs to improve health outcomes across a wide variety of chronic conditions. The following are a few such examples.

Heart Failure and Individuals with Low Literacy

Dewalt et al. [44] conducted a novel, randomized, controlled trial of a heart failure self-management program specifically designed for patients with low literacy. The authors posit that the complexity of care required for proper management of heart failure places individuals with low literacy at an increased risk for negative health outcomes such as more frequent hospitalizations, diminished quality of life, and increased mortality. Participants between age 30 and 80 with established diagnoses of heart failure were recruited and followed for 12 months. Exclusion criteria included dementia, terminal illness, substance use, severe sensory impairments, and a number of other factors such as imminent cardiac surgery and/or transplant. Pre-intervention measures included literacy assessment followed by random assignment to intervention and control groups. The intervention involved a preliminary educational session (1 hour) with a health educator in which participants received an educational booklet (written below a sixth grade level) and a digital scale and were introduced to principles of self-management. Health educators taught participants to identify signs of increasing heart failure, perform daily weight assessment, and adjust their diuretic medication based on weight fluctuations and identified symptoms. Participants with low literacy taught back the information to the health educator in order to strengthen comprehension of the material. The participant, the educator, and the patient's primary care physician worked together to establish the participant's target weight and the corresponding appropriate dose of diuretic medication. Then, the health educator and the participant created a general action plan for managing weight fluctuations (i.e., if weight increases, double the dose; if weight decreases, halve the dose). Six weekly, follow-up phone calls were made by the program coordinator to reinforce content from the educational session as well as provide support and encouragement. During phone calls, participants were asked about the self-management strategies they had utilized the previous week and were offered feedback. Participants with worsening symptoms were scheduled with their physician. There was no other specialized nursing care or medication advice. The control group received usual care. Assessment included verbal interviews in order to be sensitive to participants with low literacy. Assessment at 12 months revealed that participants in the experimental group demonstrated significantly fewer hospitalizations and deaths than the control group (65 versus 107; 3 versus 4, respectively). While there was no significant change in heart failure-related quality of life, other outcomes demonstrated improvement. Compared to the control group, the intervention group demonstrated significant improvements in knowledge, self-efficacy, and self-care behavior. Subgroup analyses based on literacy did not find significant differences between the groups. However, this finding should be considered in the context of research that shows that individuals with low literacy are at higher risk for adverse health outcomes [45]. Therefore, it is important to note that the participants with low literacy group benefitted *as much as* the participants with higher literacy. In addition to adaptations for low literacy, the intervention in this study was unique in that it taught patients how to manage their diuretic medication themselves, a strategy that may underlie the observed improvements in self-efficacy.

Childhood Obesity in a Rural Midwest Town

In this pilot study, Hawley et al. [46] applied behavioral change constructs including goal setting, self-efficacy, and readiness to change to childhood obesity prevention with unexpected results. Community-based interventions were aimed at sixth grade students and their families living in a rural, Midwest state. The project included two studies implemented over 12 months. The goal of the first study was to raise community awareness about childhood obesity, identify the scope of the problem, and establish a group of professionals in the community invested in change. The second study focused on direct intervention and utilized information gathered from study 1 to tailor intervention strategies. Intervention consisted of a five-session, middle school classroom program delivered over 6 weeks with a capstone community event (free Family Fun Night) focused on nutrition and physical activity. The five sessions occurred during physical education classes and utilized a two-pronged approach of instruction and activities. Instruction included providing information on fitness, healthy eating habits, stages of change, setting goals, and self-evaluation. Activities included investigative and experiential games and tasks. Home-based activities included a “Field Guide” with suggestions, tips, and information meant to be shared with family. Pre- and posttest measures of nutrition, exercise knowledge, attitudes, and behaviors were administered to both students and their families. Results were unexpected. Students did not demonstrate changes in attitudes and behaviors from pre- to posttest; however, results revealed significant changes among families, including increased recognition of the importance of healthy eating, increased levels of physical activity, and increased self-efficacy. Analyses demonstrated that many students began the intervention already in the action or maintenance stages of change, whereas families started the intervention in the preparation or action stages of change. Consequently, families were able to demonstrate more “movement” on this dimension than students. Additional explanations identified higher initial levels of fitness knowledge and activity levels among students than among families. While this intervention unexpectedly impacted families more than students, it highlighted the value of the community and its resources as contributors to the success of the program and provided guidance about next steps, including development of longer, family-centered approaches [46].

Adolescent and Young Adults with Sickle Cell Disease

In this feasibility study, Crosby et al. [47] evaluated the CDSMP model for use with adolescents and young adults (AYA) with sickle cell disease (SCD) using a pretest-posttest design. African-American AYA between the ages of 16 and 24 with confirmed diagnoses of SCD were referred by healthcare providers. CDSMP was conducted with no modifications for SCD. Following the 6-week program, post-intervention assessments revealed that participants were satisfied and would recommend the program to others (91%). Results also showed that AYA participants enjoyed interacting, problem-solving, and action planning with peers with SCD, as well as significant improvements in general self-efficacy after intervention with CDSMP. This example provides preliminary evidence for the utility of self-management in AYA [48].

Lower-Income, Urban, African-American Older Adults

Rose et al. [49] conducted a pilot study to evaluate the effectiveness of an approved, adapted version of the CDSMP for use with African-American older adults as part of a larger effort to examine health disparities in chronic disease conditions. Adaptations were incorporated into the modules of the standardized protocol and included emphasis on a reduction of salt and sugar (nutrition module), adding prayer (stress reduction module), and communicating with health professionals of a different race. African-American participants with at least one chronic condition (any type) were recruited for participation. Classes were conducted in a variety of community settings including senior centers, senior housing, and churches. African-American older adults in the community served as lay leaders for each of the six sessions. Results revealed significant improvements in health behaviors (at 10 weeks), practice of cognitive symptom management (at 10 weeks), and communication with one’s physician (at 6 months). Qualitative evaluation revealed excellent participant satisfaction, particularly for the enthusiasm of the leaders and opportunities for sharing during group discussions. Significant improvements in health behaviors among this sample of low-income, urban, older African Americans illustrate the potential benefits of chronic disease self-management for underrepresented and underserved populations [49].

Cost Effective

Quality-Adjusted Life-Years (QALYs)

The rapidly growing number of individuals with chronic disease has propelled substantial interest in whether chronic disease self-management programs can improve health-related outcomes while also decreasing healthcare costs. Examples of the ability of chronic disease self-management programs to improve health-related outcomes for a variety of conditions are readily available in the literature [6–8, 13, 16, 34]. While the number of studies on the cost-effectiveness of self-management programs has grown, this line of inquiry is complicated by the fact that health outcomes for self-management programs (e.g., increased self-efficacy) can be observed in the short term, whereas cost outcomes are most evident years after the onset of the condition due to the long-term nature of chronic diseases [50]. Thus, it may be difficult for organizations aiming to implement self-management programs to argue for the allocation of scarce resources for interventions that are designed to demonstrate longer-term cost savings [50]. To that end, computer simulation models have been developed that can predict the benefits in health outcomes and cost savings that would result from the intervention over a patient's lifetime, based on short-term data. A comprehensive examination of the principles of healthcare cost analysis, models of analysis, and how model parameters are calculated is outside the aim and intent of this chapter. For a thorough examination of these topics, the interested reader may consider the following reviews [51–54]. That being said, one common measure of health improvement, the quality-adjusted life-year (QALY), should be defined. The QALY is an index number based on quality of life and length of life. The QALY is determined by multiplying the utility value of a health state (quality) by the number of years lived in that state (quantity) [54]. Utility values occur on an interval scale from 0 to 1, where 0 indicates death and 1 indicates perfect health. For example, 1 year of life lived in a state with a utility of 0.5 (e.g., sick in hospital) would give (1.0 × 0.5) = 0.5 QALY. Likewise, a half-year lived in perfect health would also give (0.5 × 1.0) = 0.5 QALY [55]. In this way, researchers have a shared language for comparing the value of different interventions (i.e., cost per QALY) [51]. QALYs may also be utilized in making personal clinical decisions or insurance decisions, evaluating ongoing programs, or allocating resources. The following studies are examples in which QALYs are utilized to demonstrate the cost-effectiveness of self-management programs.

Diabetes

Brownsonet et al. [50] examined the long-term cost-effectiveness of a diabetes self-management program using a computer simulation model. Data from four sites were gathered and included organization type, population served, key self-management strategies, effectiveness of the intervention (as measured by patient surveys, change in hemoglobin levels, blood pressure, lipids, etc.), and costs associated with developing and operating their programs. These data are added to the model to create a set of assumptions used in the analyses. Based on these data, the model [56] simulated disease progression on three disease pathways: nephropathy, neuropathy, and heart disease/stroke with outcomes including disease complications, deaths, costs, and QALYs. In simulation models, outcomes are affected by interventions, such as reduced cholesterol reducing the prevalence of heart disease/stroke complications [50], which in turn had the downstream effect of increasing QALYs. The model predicted the total costs due to intervention, treatment, complications, and QALYs both with and without the self-management intervention. In this study, the model predicted an incremental increase of 0.2972 QALYs and estimated a cost-effectiveness ratio of $39,563/QALY. The authors note that while there is no universally accepted standard for cost-effectiveness ratios, costs between $50,000 and $75,000/QALY are considered acceptable in the context in which the study was performed [57]. In this study, the authors compared their predicted cost-effectiveness ratio of $39,563/QALY to a conservative ratio of $50,000/QALY, which yielded a cost saving of $10,437/QALY. Thus, based on model parameters, the researchers were able to conclude that the self-management interventions used by the four sites were significantly cost-effective over the long term when compared to usual treatment [50].

Hepatitis C

Groessl et al. [58] conducted a prospective, randomized, controlled trial that compared the effects of a hepatitis C virus (HCV) self-management program [59] to an HCV information-only group. Primary outcomes included different aspects of health-related quality of life as well as measures of HCV knowledge, self-efficacy, depression, and energy/fatigue. Cost-effectiveness was measured in QALYs. As in the previous study, total costs were calculated and included intervention costs and healthcare utilization costs. Intervention costs were personnel costs, materials, and overhead costs, as well as the cost of training for intervention staff. Health care utilization costs were derived from patients' medical records 1 year prior to the intervention and 1 year after beginning the intervention. Analyses demonstrated the information-only group gained a total of 0.0166 QALYs, whereas the self-management group gained a total of 0.0464 QALYs [58]. The difference between these figures is the incremental effectiveness of the self-management intervention, which was 0.0298 QALYs per participant. The self-management intervention also demonstrated a greater reduction in healthcare costs than the information-only group, and the cost of the intervention ($229/person) was significantly offset by the healthcare cost savings ($815/person) [58].

In-depth cost-effectiveness analyses are also available for common chronic conditions such as arthritis [60], smoking [61], and heart failure [62].

Additional Advantages

Tailorable

The studies discussed in this chapter are intended to highlight a few of the primary advantages of self-management interventions, such as their utility across the prevention spectrum, their efficacy with a diverse range of conditions and demographic populations, and their overall cost-effectiveness. For example, self-management models offer broad, general strategies for a wide range of chronic conditions, while at the same time being tailorable for specific groups. Stanford's CDSMP provides a strong example of this ability to customize the intervention for special populations. CDSMP can be offered to heterogeneous groups because it operates according to the principle that diverse groups share similar experiences [18]. However, it can also be tailored to meet the needs of specific groups. In the earlier example of a CDSMP intervention for individuals with heart failure and low literacy [44], tailoring included alterations to educational materials to accommodate lower reading levels and pedagogic techniques that involved participants conversationally teaching back learned material to group leaders. Similarly, in the prior example of a CDSMP intervention for low-income, urban, African-American older adults [49], tailoring included the incorporation of elements such as emphasis on reducing salt and sugar, adding prayer, and communicating with health professionals of a different racial/ethnic background. While offered as an example of cost-effectiveness, the hepatitis C virus self-management program [58] is also an example of a tailored approach. For this group, emphasis was placed on educational materials and skills to reduce the risk of viral transmission, given that many individuals with hepatitis C are asymptomatic until diagnosis [63]. Self-management models may also be tailored according to [64] identification of three main types of self-managers: vulnerable, confident, and moderate needs self-managers. Characteristics and preferences for support for each group suggest that knowing participants' self-management style may help target support strategies that match that style [64].

Ease of Implementation

Delivery Location

Self-management interventions can be delivered in a wide variety of settings. While first offered at clinical sites, program locations have now expanded to include patients' homes, houses of worship, schools, senior centers, and work sites. For example, the [46] childhood obesity program took place in a middle school building. Similarly, Leveille et al. [41] conducted their program aimed at preventing disability in frail older adults at community senior centers. Moreover, Samuel-Hodge et al. [65] created and tested a culturally appropriate, church-based, self-management intervention for African Americans with type II diabetes with results indicating participant satisfaction and short-term metabolic control.

Lay-Person Leaders with Chronic Conditions

Stanford's CDSMP upended models of patient education and support that required physicians and other highly skilled and costly health professionals to deliver the intervention. Developers of this model [16, 18] saw the potential value in training "everyday" people with chronic conditions to serve as group leaders. Not only does lay leadership increase the sustainability of the program while lowering costs, but also it enhances the relevance of the content when delivered by leaders who share the same struggles as participants. Cameron et al. [21] hypothesized that identification with other program members builds group-based self-efficacy which facilitates individual self-efficacy, the primary construct associated with improved physical and mental health outcomes.

Limitations

In general, Barlow et al. [12] offer a concise outline of common methodological concerns found in the self-management literature, which includes the fact that self-management programs are offered as a "package" of components [12], making it difficult to identify the exact change mechanisms involved. Other limitations include small sample sizes and relatively short follow-up intervals, given the long-term nature of chronic conditions.

Considerations

Despite the increasing popularity of self-management programs, recruiting and retaining male participants remain difficult [66]. Research shows that middle-aged and older men are less likely to attempt or complete programs than middle-aged and older women [67]. Explanations may involve men's perceptions about programs or perceptions about their own need to attend such programs. Perhaps as programs have been modified for various groups, they should also be modified to attract and meet the needs of older male individuals.

Other practical and cultural considerations have been shown to be critical, such as providing transportation or a meal at the start of each class. This was the case for a pilot CDSMP project for diabetes self-management in an urban, Native American community in California [68]. The program was cancelled following the third session due to poor attendance. Once the program was translated into a culturally appropriate framework (by the community itself), it was reattempted and found to be more meaningful for participants. Culturally relevant elements were added such as a blessing at the start of each session and a smudging ceremony at the end of each session. Meals and time for interaction were provided prior to the teaching for each class. Some outcomes of the program included increased community involvement (e.g., a community support group formed that offered diabetic-friendly food) and increased health behaviors (e.g., physical activity, making healthy food choices) [68].

Conclusions

Grounded in Bandura's theory of self-efficacy [5], self-management programs strive to empower the individual with the chronic condition. Self-management programs were designed with the knowledge that individuals are their own experts and that they are capable of identifying problems and generating their own solutions. Self-management programs have been shown to be effective across the prevention spectrum, across a wide range of conditions, and across diverse populations. Self-management programs are also cost-effective, tailorable, and flexible in their implementation. As the world's population continues to age, effective, broad, flexible, tailorable, and cost-effective strategies will become increasingly critical. Self-management programs are one such method to meet this growing need.

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Part II
The Application of Self-Management in Various Conditions

Chapter 3
Self-Management and Spinal Cord Injuries

Eugene Nizeyimana, David Moulaee Conradsson, and Conran Joseph

Introduction to Spinal Cord Injury

A spinal cord injury (SCI) is a central nervous system disorder, resulting in paralysis of the body. SCIs can be classified as traumatic or non-traumatic. Traumatic injuries occur when an external force is responsible for injury to the spinal cord or non-traumatic where injury to the spinal cord is caused either by infections, cysts or tumors, interruption of the blood supply or congenital medical conditions [1, 2].

SCIs can further be sub-classified as ***tetraplegia*** or ***paraplegia***, depending on the level of the lesion. *Tetraplegia* results in some degree of loss of function in all four limbs, while *paraplegia* results in some degree of loss of function in the lower extremities with function preserved in the upper extremities. An important property of the classification of an SCI is ***the completeness of lesion***, which is typically determined by the presence or absence of sacral sparing [3]. An SCI affects the autonomic neurologic function of the body, resulting in multiple impairments such as loss of bowel, bladder, and sexual functions [4]. Therefore, a spectrum of problems experienced by persons with SCIs is vast. Being a multi-system condition, SCI requires intensive management and access to and availability of specialized systems of care including self-management.

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Epidemiology of SCI

Understanding the distribution and determinants of SCIs is an essential step toward healthcare planning for this target group. The regional data on the incidence rate of SCI was 40 per million in North America, 16 per million in Western Europe, 15 per million in Australia, 25 per million in Central Asia, 21 per million in South Asia, 19 per million in Caribbean, 19 per million in Latin America Andean, 24 per million in Central Latin America, 25 per million in South Latin America, 29 per million in Sub-Saharan Central Africa, and 21 per million in Sub-Saharan East Africa [5]. In South Africa, a recent prospective survey indicated an incidence rate of 75.6 per million population, which was the highest in the world [6]. Although the incidence of SCI is high in South Africa, other areas of Africa report significantly lower figures – 13 and 26 per million in Botswana [7, 8] and Tanzania [9], respectively.

The prevalence of traumatic spinal cord injuries (TSCI) is believed to range from 239 to 1009 per million population [10]. This difference in reported prevalence is not only as a result of the frequency of disease occurrence but is also as a result of the different methodologies used to determine the estimates. For example, in India, the prevalence was estimated at 236 per million population but this result was based on one rural district with a population size of approximately 64,000 [11]. Consequently, this results in a knowledge gap concerning the true burden of SCIs, as well as lack of understanding of the needs of survivors at population level. This information is necessary to assist healthcare planners to build and strengthen care systems.

Consequences After an SCI

To understand the consequences after an SCI, one needs to consider conditions directly linked to SCI pathology as well as the secondary health complications. Despite significant advances made in the provision of specialized and comprehensive care to those affected with an SCI, secondary complications remain common. Reduced lengths of stay in the rehabilitation facilities have been reported to be associated with higher rates of secondary complications and subsequent high rehospitalization [12, 13].

Common SCI-related secondary complications include neuropathic and/or musculoskeletal pain, pressure ulcers, spasticity, urinary tract infections, bowel dysfunctions, pulmonary complication, sexual dysfunctions, anxiety, and depression [14, 15]. Reports in the literature have found that, on average, persons with SCIs may experience seven secondary health complications at any given time [16, 17]. These secondary complications contribute to poor health of individuals with an SCI, affecting their functional independence, limiting participation in the community and social activities that consequently lead to poor quality of life [18]. In addition to the personal impact on functioning and quality of life, the costs to the health systems and increased mortality rate are significant [18, 19].

These secondary complications and associated functional problems such as activity limitation and participation restriction can be reduced by incorporating self-management (SM) tasks and skills into the daily life of SCI survivors. There is however, limited to no information available on SM after SCI from the developing context. This information is needed to inform healthcare services, especially when survivors of SCI are discharged home and into their communities.

Self-Management Target and Associated Skills in SCIs

Self-management for persons with SCIs requires a coordinated and comprehensive approach that targets the complex interplay between the primary impairment, secondary complications, physical and psychological consequences, as well as lifestyle changes that are associated with the injury. It also requires a collaborative approach in which the healthcare system delivers on-going support for people who are living with the injury to manage their own condition [20]. Due to the complex interplay between primary impairment and secondary health complication, SM interventions designed for persons with SCIs should target both the acute and chronic consequences of the injury. At the acute stage, interventions should focus on the prevention and/or the management of the secondary health complications associated with SCIs. The programs designed for the chronic stages, on the other hand, should target the long-term consequences such as physical, psychosocial, and lifestyle changes that can negatively affect functional independence, activity, and participation as well as quality of life [21].

Self-management interventions aim to support individuals with the following three main tasks: (1) medical management of the condition, (2) coping with the effect of the condition and carrying out the usual roles and activities, and (3) management of the emotional impact of the condition [21]. These interventions could be generic or condition-specific, led by different people who could include healthcare professionals, trained volunteers, or peers. The content can be variable, either a single component or multifaceted, and could be delivered to a single individual or a group [22]. To effectively execute self-management, Lorig and Holman [23] propose that five core SM skills are needed. These generic skills all apply to living with an SCI, and addressing these require knowledge and understanding of both barriers and facilitators to each competency.

By definition, SM is problem based. Thus, problem-solving is a core SM skill. Effective SM for persons with an SCI requires not only technical skills to perform routine behaviors but also problem-solving skills to manage day-to-day barriers to routine adherence and make appropriate adjustments to self-care routines [24]. The decision-making skill is a part of problem-solving that is based on having enough and appropriate information about the condition/situation. For example, persons with an SCI may be given enough information about pressure ulcers and they are taught how to recognize when they are at risk of developing pressure ulcers and which action to take in order to prevent them from occurring.

This skill will automatically lead to the next stage, that is, action planning. Action planning involves the identification of specific, actionable goals, the identification of specific actions to work toward acheiving the goals, where, how, what frequency and the duration of the actions. This stage will eventually lead to the final skill, which is taking the action that may involve making a short-term action plan/setting goals and working toward achieving those short-term goals.

Self-tailoring is one of the other important SM skills required for an SCI. Self-management intervention designed for persons with SCIs are most likely to succeed if they address the individual's specific needs. Thus, prior to designing SM programs, the views of end users on what components should be included in the program might be needed. For example, in a Canadian study [25], individuals with SCIs highlighted that exercise, nutrition, pain management, information/education on aging with an SCI, communicating with healthcare professionals, problem-solving, transitioning from rehabilitation to community, and confidence were very important components of self-management. Participants also indicated that the program should have individuals with a similar level of the injury and a similar age group.

McIntyre et al. [26] are of the view that SM intervention programs designed for persons with SCIs should also be theory-guided to allow for the interpretation of empirical findings and to draw valid conclusions. The importance of the theory-based interventions such as Health Action Process Approach (HAPA) model [27] is to first assess the individuals' initial readiness and then evaluate behavioral change to determine whether a person intends to act on health behavior and whether they have the motivation, acceptance, and perceived control to be able to optimally engage in an SM program. Self-efficacy or confidence to perform a given task is one of the four components of social cognitive theory that is commonly viewed as the mediator between the acquisition of SM skills and the desired SM behavior [28].

An SM intervention program designed for a person with an SCI should therefore consider the specific barriers and facilitators experienced by the individual. For example, physical and emotional support from the caregiver, peer support and feedback, importance of a positive outlook and acceptance, and maintenance of independence/control over care were identified by individuals with an SCI as facilitators to SM, whereas caregiver burnout, funding and funding policies, lack of accessibility, physical limitations, secondary complications, and difficulties achieving a positive outlook or mood were identified as barriers to SM [29].

Consequences of SCI and the Impact of SM Interventions

In the following section, the possible impact of self-management on impairment, function, activity, and participation are described, as these influence the lived experiences of persons with SCIs.

Chronic neuropathic pain has been reported to be one of the major consequences of an SCI that affects approximately 70% of this population, which strongly affects daily functioning and is associated with depression, anxiety, and poor quality of life [30, 31]. Self-management programs might help persons with SCIs to adopt and adapt the strategies to improve coping mechanisms and consequently reduce pain-related disabilities [32, 33]. In addition, with chronic neuropathic pain, pressure ulcers are also common complications following an SCI. Pressure ulcers have a variety of negative effects on patients with an SCI, such as a decreased body image, low self-esteem, decreased social relationships and social activities, as well as increased hospital readmission [34]. Preventive SM behaviors can contribute to decreasing the incidence of pressure ulcers. Therefore, providing timely pressure ulcer-related knowledge to patients with SCIs could help to prevent pressure ulcers, but it is more important to help them put this knowledge into a continual practice of SM [35]. Neurogenic bladder dysfunction has also been reported as an unpleasant complication, which may disable the SCI individual's social life and negatively affect the quality of life. Intermittent catheterization is the bladder management method of choice for people with persisting urinary retention, including people with neurogenic bladder dysfunction caused by an SCI. Better SM could help people with an SCI sustain the use of intermittent catheterization [36].

Sexual dysfunction is another common health complication following an SCI reported in the literature. SM interventions addressing sexual dysfunction problems, especially in women, have been found to be effective [37].

Major depression is the most common psychological condition associated with an SCI, affecting approximately 25–30% of individuals with SCIs living in the community [38, 39]. SM interventions addressing psychological consequences associated with SCI have been found to increase coping mechanism strategies [40]. Loss of functional independence, activity, and participation in daily and social life are also major consequences of SCIs. SM intervention programs addressing activity participation could be a means of encouraging and helping persons with SCIs to engage in activities outside their homes and improve the community participation and vocational reintegration [41, 42].

Table 3.1 summarizes the few self-management intervention programs that were designed to address the consequences of SCIs at various levels.

Table 3.1 Self-management intervention programs addressing spinal cord injury consequences at various levels

Authors	SM functioning targets	Description/content	Skills/principles	Settings facilitator/tutor	Mode and duration	Outcomes
Heutinket al. (2014) [32]	**Pain symptom management** *(impairment)*	A program consisting of educational sessions and cognitive and behavior therapy	Goal setting Problem-solving Coping strategies	Rehabilitation center PT, nurse, psychologist	In person and group, internet- based Once a week for 10 weeks	Favorable long-term outcomes on pain intensity, pain-related disability, anxiety, and activity participation
Burns et al. (2013) [33]	**Pain symptoms management** *(impairment)*	The sessions included CBT, patient education, SM strategies, group discussions, and activities (group exercises and guided relaxation)	Goal setting Problem-solving Action planning Coping strategies	Hospital Rehabilitation unit PT, OT, Social worker	In person and group internet-based Twice a week for 10 weeks	Increased incorporation and maintenance of coping strategies, less pain interference, and a greater sense of control
Kim and Cho (2017) [35]	**Pressure ulcers prevention** *(impairment)*	A program consisted of education and skills training, education with computer animation, videos, phone counseling, face-to-face counseling and self-management records	Goal setting Action planning Problem-solving	Hospital rehabilitation unit Researcher (profession not mentioned)	Small- group face to face For 8 weeks	Greater improvement in self-care knowledge, self-efficacy, and self-care behaviors for pressure ulcer prevention
Wild et al. (2015) [36]	**Bladder incontinence management** *(impairment)*	A program consisted of education about catheter-related monitoring and self-management strategies, such as balancing fluids with activities, choosing the best interval for intermittent catheter, finding suitable catheter supplies, travel, preventing leaking, and identifying symptoms of urinary tract infections	Goal setting Decision-making Action planning Problem-solving Resources utilization	Online program 2 professional nurses and 2 peers	In person 1 phone call per month, 1 discussion forum per month for 4 months	The frequency of catherization every 4–6 hours increased from 71% to 77%. Self-management of neurogenic bladder dysfunction increased. Catheter related-efficacy and quality of life scores also increased

Hocaloskiet al. (2016) [37]	**Sexual dysfunction** (*impairment*)	Psychoeducational program that consisted of SCT, mindfulness-based skills and education	Goal setting Problem-solving Action planning Resources utilization	Online intervention Sexual nurse clinician and registered clinical counselor	In person 90 minutes session, once in 2 weeks for 10 weeks plus 6 months follow-up	The mindfulness-based practices (focusing, self-observation, self-touch, body mapping, judgment observations, and partnered senate focus) are beneficial for women with sexual dysfunction after SCI
Dorstynet al. (2012) [38]	**Stress, anxiety, depression management** (*psychological consequences*)	A tele-counseling program	Problem-solving Coping strategies	Home program (synchronous) Psychologist	In person Telephone call once in 2 weeks for 12 weeks	Improved mood and the use of SCI-specific coping skills
Dorstynet al. (2010) [39]	**Stress and depression management** (*psychological consequences*)	A CBT program that incorporated confidence building, education surrounding the emotional impact of SCI, stress and symptom relief and coping skills	Goal setting Problem-solving Coping strategies	Rehabilitation unit Psychologist	In person Twice a week, average of 11 sessions for 6 weeks	Improved depression scores
Šidlauski-eneet al. (2017) [40]	**Functioning** (*community participation*)	A task client-oriented program using principles of training physiology, motor learning and the use of assistive devices	Problem-solving Goal setting Resources utilization	Hospital rehabilitation unit and in community Caregiver	In groups Set of 30 minutes each, 2 sets per day for 8 weeks	Significant improvement in physical function and positive impact on perceived levels of performance and satisfaction with activities

(continued)

Table 3.1 (continued)

Authors	SM functioning targets	Description/content	Skills/principles	Settings facilitator/tutor	Mode and duration	Outcomes
Kolokowsky et al. (2016) [41]	**Functioning** *(community participation)*	A program designed to help young individuals with SCI to access and maximally utilize the services and programs that are available in the community	Goal setting Action planning Resources utilization	Community physician, vocational counselor, and rehabilitation psychologist	In person Once a week for 16 weeks	At the end of the program 40% achieved educational goals, 45% achieved vocational goals. Community integration and independence also improved after the program
Zinmanet al. (2014) [42]	**Functioning** *(community participation)*	A therapeutic education program designed to address self-management strategies to cope with impairment associated with SCI such as pain, psychological issues such as depression with the overarching goal to enhance community participation	Problem-solving Goal setting Action planning Coping strategies Communication Resources utilization	Community Occupational therapist and social worker	In person and groups Once a week, 120 minutes per session for 12 weeks	At the end of the program, there was improved skills and knowledge on how to better manage the emotional, environmental, and social stressors that challenge community participation. Self-efficacy and positive affect also improved

CBT cognitive behavioral therapy, *OT* occupational therapist, *PT* physiotherapist, *SCI* spinal cord injury, *SCT* social cognitive theory

Need for Self-Management Integration in SCI Rehabilitation

The chronic nature of secondary health conditions has led to the conclusion that an SCI should be seen as a chronic condition, rather than an incidental trauma. This indicates the crucial role and responsibilities that individuals with SCIs themselves have regarding the lifelong maintenance of their own health and participation in society [43]. Integrating SM into existing SCI rehabilitation services can reduce the occurrence of these health complications which in turn will reduce the negative consequences that are associated with SCI. However, if one accepts that SM interventions can positively affect both the long-term outcomes and reduce costs associated with an SCI, then the question remains how SM can be integrated into the existing health system. In order to effectively integrate SM into the existing health system, Lorig and Holman [23] propose that at least three steps are needed: (1) preparation of the health system, (2) preparation of patients, and (3) payment mechanisms.

Preparation of the Health System

As the majority of SCI survivors in low- to middle-income countries depend on public services, the first step to integration of SCI self-management into SCI rehabilitation services is that the role of SM needs to be understood, endorsed, and supported by senior managers and policy-makers in public health. This means that health policy-makers should revisit the existing policies and include SM as an important part of rehabilitation services for persons with SCIs. The evidence of SM as a feasible and low-cost intervention in the management of SCI is increasing. However, the utility of SM among healthcare providers requires further investigation in order to inform more widespread awareness and uptake. In addition, self-management should be incorporated into health professional curricula since programs are starting to acknowledge the importance of taking a behavioral approach to treatment as well as prevention. Furthermore, health professionals who are already providing health care should be trained on SM skills that can be incorporated into all levels of SCI rehabilitation. Referrals for SM education should be standard for judging quality of care. There is also a need to work with the Joint Commission on Accreditation of Healthcare Organization (JCAHO) to encourage consistent effort to engage individuals with SCI in issues associated with improving the quality and safety of their healthcare.

Preparation of the Patients

A closely aligned facet of SM implementation is the preparation of individuals with SCIs and their acceptance of a new self. Assisting individuals to accept and adjust to a different level of functioning after an SCI is the first step that is very important for the management of the secondary consequences of an SCI. Thus, providing persons with SCIs with the necessary skills needed to be actively involved in the management of their own health condition is a vital priority. As self-management is more of a behavioral change, the most important component of the initial process would be a detailed assessment of a patient's readiness and behavioral change evaluation. The initial assessment of a patient's needs would facilitate the design of an effective individualized (self-tailored) SM program. Prior to the implementation of an SM program, healthcare professionals should consider the patient's understanding and interpretation of SM components. It is also important to assess the cognitive demands of behavioral change to ensure adherence and appropriateness of SM programs. In addition, patient-specific barriers and facilitators must be accommodated as well.

Payment Mechanisms

Although evidence exists that self-management improves health status and chronic illness symptoms while showing promise for lowering healthcare costs [44], many governments in low- to middle-income countries do not have plans in place for financing self-management programs. In addition to a lack of government support, private health insurance does also not cover self-management programs. Such services are very important for self-management programs to be successful. Allocating resources to SCI self-management programs with the goal of population-based health management will facilitate in lowering the overall healthcare costs associated with SCI consequences while improving quality of life. Therefore, self-management programs designed for individuals with SCIs should be funded like any other healthcare services, including medical aid coverage.

Conclusion

This chapter described spinal cord injury and its consequences. It then provided an overview of self-management in relation to the chronic conditions, self-management targets, as well as the associated skills and effectiveness of self-management interventions on SCI outcomes. Goal setting, action planning, problem-solving, decision-making, coping strategies, and resources utilization were the skills most targeted during SCI self-management interventions. Although the programs identified seemed to be cost-effective, the use of SM in low- to middle-income countries is limited, indicating that SM is not yet fully included in healthcare systems despite its theoretical underpinnings and empirical support. This is surprising since institutionalized care for SCI is curtailed by human resources, infrastructures, and lack of uptake of best practice guidelines. There is a need to advocate the adoption or contextualization of promising available SM programs for use in resource-constrained settings.

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Chapter 4
Self-Management in Diabetes

Thandi Puoane and Lungiswa Tsolekile

Introduction

Diabetes is a chronic metabolic condition which is characterized by an increased blood glucose level as a result of either the inability of the body to produce insulin at all (type 1) or inability to use insulin effectively (type 2) [1]. The prevalence of diabetes has rapidly increased globally. It was estimated to be 2.8% in 2000 and 4.4% in 2030, respectively. The total number of people with diabetes is projected to rise from 171 million in 2000 to 366 million in 2030 [2]. According to the International Diabetes Federation (IDF), type 2 diabetes accounts for 90% of all diabetes cases [3]. In 2019, 79% of adults with diabetes were residing in lower- to middle-income countries (LMICs) [4]. The rising numbers of diabetes patients suggest that intervention strategies are needed, especially in LMICs, where the highest numbers of diabetes cases are reported.

The treatment of diabetes does not only include glycemic control through diet and physical activity but also the prevention of complications and rehabilitation where needed. In addition, the patient needs to make decisions about drug administration, therefore forcing patients to be actively involved in managing their condition.

Describing Self-Management of Diabetes

Many countries around the world have developed guidelines for diabetes management. These guidelines provide insight into the management of diabetes to healthcare staff. As part of the guidelines, people with diabetes are meant to receive diabetes self-management education (DSME) which is directed at empowering the

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person with diabetes with the knowledge, skills, and motivation needed to perform appropriate self-care [5].

Self-management of diabetes requires the adoption of certain behaviors. According to the American Diabetes Association, self-care behaviors are positively correlated with good glycemic control and a decrease in the development of complications [6, 7]. Diabetes self-management focuses on components such as healthy eating, physical activity, tobacco smoking cessation, weight management, medication adherence, self-monitoring of blood glucose levels, blood pressure and feet, as well as routine screening of eye and renal complications [8]. Apart from these components, self-management also requires patients to deal with symptoms and disability if and when it arises, manage complex medication regimens, and adjust to the psychological and social demands the disease causes [9, 10]. The chronicity of diabetes requires patients to be adequately empowered and supported to manage their condition to improve health outcomes and prevent complications.

Empowerment Approaches for Diabetes Self-Management

Two empowerment approaches have been used to enhance the self-management of diabetes. These approaches are Diabetes Self-Management Education and Diabetes Self-Management Support.

Diabetes Self-Management Education (DSME)

Diabetes Self-Management Education (DSME) is an ongoing process of facilitating the knowledge, skills, and ability necessary for diabetes self-care. DSME is patient-centered as it commences with the patient's understanding of diabetes and perceptions of its management, including health outcomes. The main objectives of DSME are to assist the patient in making an informed decision about self-care behaviors and problem-solving and to improve clinical outcomes, health status, and quality of life [11].

Several strategies are used to deliver self-management education content, including written material available in brochures or pamphlets, which are often distributed at the health facilities for the patients to take home. Some educational materials are pre-recorded and delivered through videos which can be accessed at a patient's convenience. Education may be delivered face to face or telephonically by a health worker, and sometimes a combination of both is employed.

In many settings, nurses and doctors offer diabetes self-management education. However, in developing countries such as South Africa, diabetes education is mainly delivered by nurses. It is important to note that education usually happens in facilities and delivered to type 1 and type 2 diabetes patients as well as patients with other non-communicable diseases [12]. It is crucial to have community interventions that focus on diabetes education as they will provide a platform for clients to interact with the facilitator and clear any misconceptions and myths they may have.

Diabetes Self-Management Support (DSMS)

In recent years, there has been a shift from Diabetes Self-Management Education (DSME) to a more person-centered and theoretically based approach. This approach requires a collaboration between health worker and patient; it also uses a theoretical framework that is based on targeted self-directed behavioral change. DSMS focuses on continuous support, targeting the behavioral change that may have resulted from diabetes self-management education [13].

The initial step in utilizing a person-centered or collaborative approach in self-management is an understanding of the patient's context, as well as the available support from friends and family that may influence self-management of the condition by the patient. This should be followed by problem identification from the patient's point of view as well as the medical problems identified by the physician. The next step is the goal and objectives setting, and the development of realistic action plans to achieve the targeted objectives. The action plans should be developed, taking into consideration the patient's context and readiness to absorb the necessary information. This leads to the development of a self-management education and support strategy that will ensure continuous emotional and psychological support to assist the patient to make the required behavioral change. During this process, follow-up should be sustained to check progress in the implementation of action plans and monitor any complication that may arise [14, 15].

One example of the program that helps people with diabetes to self-manage their chronic conditions is the Stanford Chronic Disease Self-Management Program (CDSMP) which has already been proven to be effective for different conditions [16].

This program assumes that people with chronic conditions have similar concerns and have the ability to take responsibility in managing their health. It is facilitated by peer leaders who have chronic diseases and have been trained for accreditation as facilitators. They offer support to a small group of about 10–12 people on a weekly basis. The group meetings provide a platform for discussing several issues related to the management of the disease and techniques to deal with problems such as frustration, fatigue, pain, and isolation; appropriate exercise for maintaining and improving strength, flexibility, and endurance; appropriate use of medication; communicating effectively with family, friends, and health professionals; nutrition; decision-making; and how to evaluate new treatments [17].

Interventions that support individuals to achieve goals and objectives for diabetes management have utilized theories to guide educators or health professionals on how to interact with patients. These theories have also been used to guide the development of the content of educational materials.

Theories and Models Relevant for Diabetes Self-Management

There are numerous theories that people can utilize in self-management empowerment. Among others, these include self-determination theory, self-efficacy, the chronic care model, and the illness representation model.

Self-Determination Theory

The self-determination theory suggests that an individual is likely to be motivated (autonomy motivation) to acquire the knowledge and skills necessary for the adoption of the new behavior, provided that the individual understands the benefits in adopting a new behavior [18]. Diabetes patients with autonomous motivation will initiate specific diabetes self-management behavior because they see value in assuming the relevant behavior. Despite the importance of the intrinsic factors in motivating individuals with diabetes, autonomy support has a role to play in self-management. Autonomy support refers to the degree to which healthcare providers and other social support sources, such as family, understand the patients' diabetes-related priorities and needs, acknowledge the patients' feelings, offer relevant information, provide meaningful self-management choices, and avoid controlling the patients' behavior [19].

Based on the UK Medical Research Council (UK MRC) framework for developing and evaluating complex interventions, promoting autonomy motivation among patients should take into consideration local circumstances rather than being completely standardized [20].

The Self-Management and Reciprocal Learning for the Prevention and Management of Type 2 Diabetes (SMART2D) is an example of a project which was adapted for each context and implemented in three different settings, namely rural communities in Uganda, an urban township in South Africa, and socioeconomically disadvantaged communities in Sweden [21]. The interventions were developed in different phases and targeted newly diagnosed diabetic patients. The initial phase included a situational analysis of the context to understand the critical elements in the development of the interventions. The information collected from the situational analysis informed the development of the interventions. To promote autonomous support for diabetic patients, the interventions were focused at the health facilities where patients were seen; peer group support was offered by community health workers who are already diagnosed with diabetes, and companion care support was offered by either a friend or a family member. Attention was also put on increasing people's understanding of the benefits of eating a healthy diet and on making healthy food choices [22].

Self-Efficacy Theory

This theory was developed by Bandura in 1997 and describes individuals' sense of competency to perform or attain certain behaviors. In diabetes self-management, when a person feels confident in their ability to manage the disease, the person is likely to take control of the condition. A person with a good sense of self-efficacy feels confident that he/she will correctly perform the required activities. These activities include, among others, administering medications, making healthy diet choices, and engaging in physical activity to control the condition [23]. In poorly resourced areas, where patients of low-socioeconomic status often reside, barriers to self-efficacy include the food environment that promotes unhealthy food choices, crime, and an unsafe environment which does not encourage physical activity.

To overcome these barriers, community support groups for people with chronic diseases facilitated by community health workers provide a context-informed platform for learning practical tips on how to make healthy food choices and how to increase physical activity [24]. Participating in these activities assists individuals to develop self-efficacy.

Chronic Care Model

The Chronic Care Model (CCM) is an approach to reorganize primary healthcare and apply elements that allow it to respond proactively to the needs of patients with non-communicable diseases (NCDs). The CCM further suggests several interconnected elements that influence the improvement of the health outcomes of patients with chronic illnesses such as diabetes. These elements include self-management support, clinical information systems, delivery system redesign, decision support, health care organization, and community resources. If all these elements are adequately implemented, they ensure that the patient has access to additional information about the condition and receives continuous communication and support from the health professionals [25, 26]. The application of such a model has its challenges, especially in areas where resources to assist patients self-manage are scarce, such as devices for monitoring glucose levels.

Illness Representation Model

The illness representation model suggests that people have beliefs and expectations about their illness that may be associated with how they adhere to prescribed treatment as well as to the self-management of their condition. This model is central to Leventhal's Self-Regulation Theory, which states that if individuals view illness as a threat (illness representation), they will either select positive strategies and activities to help them cope with it or surrender and not act to improve their condition [27].

The beliefs individuals hold may be related to a lack of understanding of the actual causes and physiological aspect of the disease. This means there is a need for health care providers to educate the individual about the pathophysiology of conditions such as diabetes. However, it is known that in many poorly resourced areas, patients have low literacy levels, which affect their understanding of health concepts. In addition, health facilities are overcrowded and overburdened by other conditions leaving health professionals with little time to spend with each patient. Therefore, it is crucial to consider innovative ways of imparting knowledge about diseases, including the use of technology to manage such diseases.

Although the theories and models of empowerment described above may assist health personnel to understand why it is easier for some patients to adhere to self-management than others, there is also a need to understand factors that may facilitate or hinder adherence to self-management.

Based on the fact that different factors shape people's behavior, facilitators and barriers to diabetes self-management are examined utilizing the socio-ecological model. This model emphasizes multiple levels of influence (such as individual, interpersonal, organizational, community, and public policy) and the idea that the social environment shapes behaviors [28].

Facilitators of Self-Management

Individual Influences

The Role of Spirituality and Faith in the Lives of Individuals

Patients who have strong religious beliefs often attribute positive behaviors toward managing their condition as due to God's assistance. Patients believe that through prayers, God gives them the strength and comfort they need to deal with their condition [29, 30].

General Knowledge About the Diseases

Having a general knowledge as well as a specific knowledge about diabetes has been reported to assist patients to manage their disease better. A study that investigated facilitators and barriers related to diabetes self-management found that knowledge about the disease was associated with the participant's perceived self-efficacy to manage diabetes. The patients also reported that they had obtained additional information to that provided by health workers from the internet and social media [31].

Family Support

Many participants with type 2 diabetes find it challenging to adhere to diabetes management guidelines on their own and feel that family support is a critical aspect in their self-management of the disease. In a study that explored facilitators and barriers to diabetes self-management [31], participants expressed appreciation because they received support from family members with activities such as administering medication or reminding them about taking medication in a timely manner.

Community Influences

Peer Support

Peer support may be offered by people who have diabetes and are experienced in managing the condition. They may provide ongoing support to help the patient sustain the required behavior in the management of diabetes. Peer support groups offer an opportunity to share information and gain knowledge. They may support the patient socially and emotionally to deal with negative emotions. Those who provide support may also assist the patient to connect with the clinic staff when it is needed and to access other community resources. In LMICs, Community Health Workers (CHWs) play a crucial role in supporting diabetes patients with self-management [21].

Organizational Influences

Strong Commitment to Health Practitioner

Patients who have a longstanding relationship with their physician, nurse, or other health care provider and feel supported in addressing their ongoing needs and challenges are likely to adhere to and sustain self-management behavior [30].

Barriers in the Self-Management of Diabetes

A Lack of Motivation and Understanding of the Condition

A lack of understanding of the benefits of self-management in diabetes prevents patients from adhering to treatment. This is more evident in people of low socioeconomic status who are financially constrained and may lack confidence in their ability to self-manage the disease [31]. Sometimes patients lack the will to change their behavior, as they feel that there is a lot of information to absorb and that they are overwhelmed by it [32, 33].

Insufficient Understanding of the Causes and the Treatment of Diabetes

An insufficient understanding of the causes of and appropriate diabetes treatment could lead to poor adherence to diabetic treatment guidelines. A study by Masupe et al. [34] reported that people who believed that diabetes was due to bewitchment tended to use traditional or religious remedies instead of prescribed medication. However, patients thought that it was normal for older people to get type 2 diabetes. In another study that examined patients' and providers' perceptions of diabetes self-management among socioeconomically disadvantaged communities in Stockholm, it was found that patients who had seen old relatives with diabetes acknowledged that one has to live with diabetes for life. Also, patients saw diabetes as less threatening than cancer and high blood pressure [31].

Time Constraints

Management of diabetes requires regular monitoring of blood glucose levels and careful planning of a healthy diet. In a focus group discussion to explore facilitators and barriers to self-management of diabetes, participants stated that the management of diabetes consumes their time and this is frustrating, as they are sometimes not able to engage in other leisure activities. Some felt that managing diabetes was unpleasant as it controls their lives [35].

Lack of Self-Control

Since diabetes management requires patients to have a restricted diet in terms of carbohydrates and sugars to assist the body in the utilization of insulin, some participants find it challenging to follow diabetes dietary requirements, especially when food high in carbohydrates and sugar is present at events such as family gatherings and community celebrations [35].

Memory Failure

Some patients often fail to take their medicine or test their glucose levels regularly because of forgetfulness. Some participants often forget to eat regularly and do not remember until they experience symptoms of hypoglycemia [36]. Skipping of meals may lead to poor glycemic control and therefore the inability to manage the condition.

Difficulty in Changing Lifestyle

Some patients find it difficult to change their lifestyle after being diagnosed with diabetes. For example, a study by Aweko et al. [31] that explored dilemmas to self-management among patients reported that some patients found it challenging to fit the diet and physical activity recommendations into their day-to-day life. As a result, some patients decided to adopt only practices that they thought to be manageable for their lifestyle [31].

Structural/Environmental Influences

Access and Cost to Healthy Food

Due to the changing food environment in LMICs, calorie-dense food is cheap and easily accessible, while healthier food options are often expensive. This makes it difficult for patients who are socioeconomically disadvantaged to make healthy choices about food [37]. Since patients with diabetes have to change their diet, it is challenging for the poor and unemployed to adhere to dietary recommendations due to financial constraints.

Health and Economic Factors

Uncontrolled blood glucose may, in the long run, lead to complications such as damage to large and small blood vessels, leading to heart attack and stroke, and problems with the kidneys, eyes, feet, and nerves.

Since patients need regular follow-up to monitor their condition and effects of the medication, those without sick leave benefits may find themselves losing income due to absenteeism. This may, in turn, affect the family's living condition as they have to sacrifice for the well-being of the diabetic patient in terms of food and medication where applicable.

Organizational Barriers

Health Service Constraints

Some health facilities are overcrowded, leading to long waiting times. Furthermore, the communication approach often used by healthcare providers does not optimize patients' involvement in their care. The inability of health providers to communicate effectively with patients is particularly common, as providers are often inadequately equipped with the skills to handle patients from different cultures and the social aspects of self-management [31]. In such instances, patients may find it difficult to connect the information given with the necessary lifestyle changes related to the condition.

Despite the barriers faced by patients in the management of their conditions, and the difficulties faced by health workers in dealing with patients with chronic diseases in poorly resourced areas, there is global commitment to implement the strategies that will reduce the burden of NCDs such as diabetes. Furthermore, governments and global agencies have developed policies related to the reduction of morbidity and mortality due to non-communicable diseases.

Interventions to Address Non-communicable Disease

The World Health Organization's Global action plan 2013–2020 for the prevention and control of non-communicable diseases (NCDs) was developed after heads of state and governments agreed in the United Nations Political Declaration on the Prevention and Control of NCDs to support national efforts to deal with NCDs (diabetes, cardiovascular diseases, chronic respiratory diseases, and cancers) [38].

In addition, the Sustainable Development Goal (SDG) target 3.4 aims to reduce premature mortality from non-communicable diseases (NCDs) by a third by 2030 and to promote mental health and well-being [39]. This SDG forces many countries to rethink their approaches to NCDs and to explore interventions aimed at assisting patients to manage their conditions.

For example, in the South African approach, the National Department of Health has developed a Strategic Plan for the Prevention and Control of NCDs (2013–2017) [40], which is utilized to guide the interventions for the prevention and control of NCDs including diabetes. This policy guideline addresses three distinct areas of intervention: (1) the prevention of NCDs and the promotion of health at a population, community, and individual level to address the broader social determinants of health, (2) improved control of NCDs through the strengthening of the primary health system, and (3) comprehensive monitoring of NCDs and their risk factors [40].

In an effort to improve the management of chronic conditions in South Africa, the National Department of Health adopted an Integrated Chronic Diseases Management (ICDM) model [41]. The ICDM is a public health approach to empower the individual to take responsibility for their health, with interventions implemented at a community/population and health service level. The ICDM aims to achieve optimal clinical outcomes for patients with chronic communicable and non-communicable diseases. This model is an innovative, efficient, and cost-effective response to the growing burden of disease. The ICDM consists of four inter-related intervention phases (facility reorganization, supportive clinical management, assisted self-support, and strengthening of support).

The implementation of the ICDM is facilitated by the primary health care outreach team who educate patients and communities to take responsibility for their health. As part of the primary health care re-engineering, community health workers are part of Ward-Based Outreach Teams and serve as a link between the community and the health system. They also visit the patients to ensure that they adhere to prescribed medication and monitor relevant anthropometric measurements to identify complications and refer patients to a health facility if needed. To keep the patient connected with other patients with the same condition, the community health workers also assist linking the patients to age-appropriate patient support groups and adherence clubs [40].

These government initiatives are supported by several interventions aimed at improving adherence to self-management in patients with chronic diseases including diabetes.

Interventions for Self-Management

Several interventions for self-management in diabetes have been developed in high-income countries. The maintenance of good glycemic control through self-management has been found to reduce the complications associated with diabetes significantly [36, 37, 42, 43]. Self-management and maintaining ideal glycemic control are complex and therefore many people with diabetes struggle to manage their condition. Interventions in many high-income countries directed at self-management focus on problem-solving, peer support, and coaching [32, 44, 45], patient education [46, 47], and lifestyle modification and tend to utilize technology to deliver the interventions.

Interestingly, many of the interventions in high-income countries use highly skilled professionals such as nutritionists, nurses, or other types of health professionals like psychologists to deliver them [48]. The use of health professionals, especially nurses, poses a challenge for low- and middle-income countries where there is a shortage of nurses and other types of health professionals such as psychologists. This challenge suggests the use of different kinds of health workers, such as health promoters and community health workers (CHWs) to deliver interventions. An example of such an intervention is a pragmatic cluster randomized controlled trial that utilized health promotion officers to offer four sessions of group diabetes education in a guiding style [49]. Moreover, this trial showed that group education rather than individual sessions might be ideal in a resource-constrained setting.

Despite the plethora of interventions from high-income countries directed at assisting people with diabetes to self-manage their conditions, they are tailored toward people with higher socioeconomic status. Nonetheless, LMICs can still learn from the implementation of these interventions. Furthermore, they can adapt some of the interventions to be better suited for developing countries. The adaptation of the Diabetes Prevention Program (DPP) developed by the Center for Diseases Control for use by CHWs in South Africa is an illustration of the kind of adaptation process required to deliver an intervention in a setting with individuals of low literacy. In the adaptation of DPPs, CHWs were used as facilitators for group discussions, and videos were used to deliver expert content. The intervention was delivered in the local language, and the program used culturally appropriate foods as well as videos and stories that are culturally sensitive [24]. The adaptation process provided a two-way learning opportunity for the professionals from the developed nations and from low- to middle-income countries.

Conclusion and Recommendations

The key to the management of diabetes is to improve self-management by empowering patients to manage their condition, and effective self-management requires health professionals to work in collaboration with patients. Nurses based in primary health care facilities are crucial in equipping patients with self-management skills, and they require knowledge and training to communicate effectively with patients. Empowering the patient to take control of managing their condition should also be accompanied by continuous support from health workers, peers, and family. There is, therefore, a need to develop interventions, especially in LMICs that utilize other groups of health workers such as CHWs and health promoters as there is a shortage of health professionals, especially nurses. Interventions from high-income countries are useful, but they ought to be adapted to suit the context in LMICs. In developing interventions to improve diabetes self-management, factors that may facilitate or discourage adherence to a treatment regime should be taken into consideration. These factors include interacting influences at the individual, community, and structural levels.

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Chapter 5
Self-Management and Stroke

Anthea Rhoda, Ryan Groenewald, Reham Altigani, and Fiona Jones

Background of Stroke

The World Health Organization defines stroke or cerebrovascular accident as “a focal (or at times global) neurological impairment of sudden onset, lasting more than 24 hours (or leading to death), and of presumed vascular origin” [1]. A stroke, part of the cardiovascular disease category of non-communicable diseases, occurs as a result of a hemorrhage (hemorrhagic stroke) or a clot (ischemic stroke). Stroke contributes to 6.7 million deaths annually [2]. Stroke is the second leading cause of death and the third most common cause of disability-adjusted life-years (DALYs) globally [3]. DALYs is an important measure as it highlights the number of years lost due to ill health, disability, or premature death [4]. In 2016, there were 80.1 million (74.1 to 86.3) cases of stroke globally [5]. The true impact of stroke does not lie in the high mortality rate, but rather the high morbidity rate, whereby up to 50% of patients with stroke are left chronically disabled [6]. A number of risk factors for stroke have been identified. These include non-modifiable risk factors such as age, sex, and ethnicity, while commonly documented modifiable risk factors for stroke include hypertension, smoking, diet, and physical inactivity [7]. The modifiable risk

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factors are the focus of stroke prevention programs, as they can be addressed by lifestyle changes using behavioral modification strategies and could contribute to decreasing the occurrence of stroke [8]. These stroke intervention programs should include a focus on stroke in young adults (18–50 years) as the incidence of stroke in this group of the population is increasing and their risk factor profile mainly includes modifiable risk factors [9].

Impact of Stroke

Disability post-stroke can be conceptualized within the framework of the International Classification of Functioning Disability and Health [10]. The International Classification of Functioning, Disability and Health (ICF) is a framework for describing and organizing information on functioning and disability. It provides a standard language and a conceptual basis for the definition and measurement of health and disability. Within the ICF, human functioning is identified at three levels, namely functioning at the level of body or body part, the individual, and the whole person in a social context. Disability results from dysfunction at any one of these levels, following impairments at the level of the body part or body system, activity limitations which affect the whole body, and participation restrictions when an individual is challenged to engage and participate in society [10].

Impairment

Impairments following a stroke are heterogeneous, and presentation depends on the particular regions of the central nervous system (CNS) that have been damaged [11, 12]. Stroke patients can have a varied number of impairments, with some experiencing more than 10 different impairments [13]. Impairments that are common after stroke include weakness especially of the upper limbs, urinary incontinence, impaired consciousness, as well as dysphagia [14]. Approximately 35% of survivors with initial paralysis of the leg do not regain useful function, with 65% not being able to functionally use their upper limb at 6 months post-stroke [15]. Thirty percent of patients with stroke could also experience aphasia [16]. Impairments are also known to impact the individual's ability to perform functional activities and participate in specific life roles [17, 18].

Activity Limitations

Activity limitations include challenges to perform basic as well as instrumental activities of daily living. Basic activities of daily living include feeding, bathing, dressing, bowel and bladder control, toileting, transfers, mobility, and the ability to climb stairs [19], while instrumental activities of daily living include activities such as cooking, shopping, and using public transport [20]. Stroke can cause profound impact on an individual's ability to independently perform self-care activities, and 25% will need assistance from caregivers in the longer term [21]. Almost half of stroke survivors require some (mild to moderate) assistance with the basic activities of daily living as long as 1-year post-stroke, while the majority would need full assistance (complete assistance) with instrumental activities of daily living [20]. People with stroke might be able to function within their homes but could find it difficult to function beyond their homes in the community. This would mean they could be independent in performing basic activities of daily living but struggle with instrumental activities of daily living [20].

Participation Restrictions and Quality of Life

The dimensions of participation include community life, leisure, educational and occupational activities, social integration, and economic self-sufficiency [10]. A marked decline in active leisure participation is often experienced after stroke, regardless of motor function [22]. Return to work is also decreased after a stroke. Up to 60.8% report inability or reduced ability to return to work [23]. A number of factors have been identified that influence community participation of patients with stroke. These include attitudes of others, access to transportation, and Social Security Services [24]. Other predictors of community participation identified by Elloker [25] included mobility, cognition, life activities, and stroke risk factors. In most studies where the social impact of stroke was investigated, it was reported that restrictions in participation following stroke negatively impacted quality of life [26]. In addition to community participation, a number of factors have been identified that could impact quality of life in patients with stroke. These include walking speed, where individuals who had a higher walking speed reported a better quality of life [26]. On the other hand, patients with stroke who were dependent on others to perform activities of daily living had lower scores in all the domains of quality of life [27]. It was reported that those who needed assistance with performing activities of daily living had higher anxiety and depression scores as measured by the Hospital Anxiety and Depression Scale (HADS) than those who were independent in these activities.

The Impact of Stroke on Caregivers

Stroke does impact not only the individual but also the caregivers of these individuals. Aspects that are impacted include the physical and mental health of the caregiver as well as the relationship between the caregiver and the individual with stroke [28]. If employed, the employment status of the caregiver could also change as a result of the amount of time needed to provide care. It is important to note, however, that caregivers play an important role in the rehabilitation of the patient with stroke. The amount of care needed and provided also differs depending on the recovery trajectory of the patient. Caregiving has been described as higher directly after discharge, but the impact could remain high up to 1-year post-stroke and longer [29].

Self-Management for Patients with Stroke

Self-management as defined by Barlow et al. [30] is described as "an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic disease." A Cochrane review conducted by Jones and Riazi [31] reported that self-management programs may be beneficial to community-dwelling stroke patients and can impact their quality of life and self-efficacy. Hence, a self-management intervention focused on supporting an individual's self-efficacy and confidence to solve problems and construct their own action plans could help address the challenges experienced by stroke survivors when they are discharged from rehabilitation programs [32]. A number of different interventions/activities supporting self-management have been described in the literature. The strategies applied in self-management programs have included the use of workbooks, videos, and quizzes which facilitate problem-solving and self-efficacy [31–33]. Group self-management programs can be facilitated by health professionals, lay people, or peers. An intervention aimed at facilitating principles of self-management is generally provided over a number of sessions rather than a one-off session [29, 31, 32]. It is also important to consider stroke survivors with aphasia when implementing self-management programs [34].

Integration of Self-Management Principles in Stroke Rehabilitation

Evidence exists that self-management approaches can be more effective when they are tailored to individual needs. It is also suggested that self-management programs should not be seen as an "add on" to care, only applied once the patients are discharged from rehabilitation, but and should be integrated into stroke rehabilitation starting with the first engagement between the therapist and the patient [35]. Self-management support also requires knowledge and skills by healthcare staff to integrate and adjust strategies to the needs of individual patients [36]. Self-management could also result in the reduction in the use of healthcare resources [37].

The Bridges Self-Management Program is a self-management program developed for people post-stroke and can be both tailored to individual needs and integrated into the rehabilitation process. In this program, the use of mastery experiences which help to strengthen an individual's self-efficacy, are built into rehabilitation sessions, and clinicians are trained to facilitate crucial self-management skills such as problem-solving, reflection, and self-discovery [38] (see Table 5.1). There is a strong emphasis on clinicians finding out “what is important to patients” and shaping rehabilitation interactions so that they focus on meaningful goals and support confidence to self-manage. This provides the basis for a collaborative and therapeutic relationship, in which rehabilitation plans are devised and planned together. A vital aspect of this approach is that patients understand their own contribution to progress and self-management [33], as management of their condition by the individual is central to the self-management process.

Social cognition theory and self-efficacy have informed the development of the Bridges Self-Management book which has been co-produced with stroke survivors and incorporates the principles of mastery and modeling – two important sources of self-efficacy. Originating from Bandura’s social learning theory which later developed into social cognitive theory, it is believed that the level of self-efficacy can help to predict not only the outcome but also an individual’s outcome expectations. Social cognitive theory and the principles of self-efficacy such as goal mastery and vicarious learning are recognized as important bases for the success of many self-management programs. Some evidence also exists which supports the relationship between self-efficacy and functional capability post-stroke [34]. Other areas such as depression and quality of life are also associated with self-efficacy [34]. The level of self-efficacy is therefore affected by psychological and emotional state, with self-efficacy being higher when levels of depression are lower. Hence, self-management programs that focus on improving an individual’s self-efficacy could result in positive physical and psychological outcomes [39].

The Bridges Self-Management book contains vignettes of people with strokes, accounts of their experiences, practical ideas and inspiration to support problem-solving, goal setting, and taking action. There is also space for users to record their goals and progress, and to reflect on experiences and crucial information to help knowledge and understanding about recovery after stroke. The book is a tool to aid self-management and can be used flexibly as a resource by users [40]. A recent version of the Bridges Self-Management Program was made more accessible to people with stroke and aphasia by co-designing aspects of the content, layout, and accessibility [41].

McKenna et al. [42] provided preliminary evidence suggesting that the implementation of a stroke self-management program was acceptable and could impact self-efficacy [42]. The support for the link between self-management and self-efficacy was based on a systematic review conducted by Jones and Riazi [31]. Furthermore, a feasibility randomized controlled trial conducted by Jones et al. [35] provided some evidence that there appeared to be greater changes in functional activity, self-efficacy, of the participants who participated in the Bridges Self-Management Program compared to a control group. In a cluster randomized controlled trial, conducted in 2016, Jones and Riazi determined the feasibility of integrating the self-management program into community stroke rehabilitation [31]. Besides building the evidence base for the Bridges Self-Management Program, a qualitative study revealed that patients with stroke, their carers, as well as health professionals reported that the program was acceptable and beneficial [42]. Patients who had received rehabilitation with self-management support perceived a greater sense of responsibility, control, and acknowledgement of their previous skills [37]. It is, however, important to note that a “one-size-fits-all” approach cannot be adopted when applying this approach, as stroke impacts individuals differently, including having cognitive and emotional challenges. Skills in coaching and guiding individuals’ confidence to self-manage are needed by therapists to work collaboratively and engage the patient in the process [43].

The Bridges Self-Management Program is supported by a growing evidence base [31, 33]. This approach is based on a number of vitally important principles which can be applied during the rehabilitation of individuals with stroke (see Table 5.1).

Contextualization of the Bridges Self-Management Program in Different Settings

The Bridges Self-Management Program has now been applied across several stroke services in the UK and adapted to other conditions such as brain injury and multiple trauma, as well as being contextualized to other settings and cultures such as New Zealand, Australia, and South Africa [44–46].

In the contextualization of the Bridges program in New Zealand, the acceptability and relevance of the approach were explored using a qualitative research approach, with interviews conducted with both neurorehabilitation therapists as well as patients with stroke. Stroke survivors’ perceptions of the adapted program were also explored. Findings from this study highlighted the importance of including “stories” that were relevant to the local context and setting. Overall, New Zealand stroke survivors felt that the Bridges program highlighted the importance of confidence in one’s own skills and how to support your own recovery [44]. When the Bridges program was adapted in Australia, the authors conducted a survey among stroke professionals who attended a Bridges Training Program on their attitudes toward and understanding of self-management and the perceived barriers to the implementation of self-management support. Health professionals reported that post-training they promoted self-management and felt confident that they could apply self-management principles such as goal setting and problem-solving. In addition to the survey focus group, discussions were held with patients with stroke living in the community. They were provided with a copy of the Bridges Workbook 2 weeks prior to the focus group discussion. The stroke survivors agreed with the professionals about the timing of the intervention, starting earlier rather than later. Furthermore, they indicated that the book should include aspects of “emotional management.” When they engaged with the workbook, they reported the aspects of reflecting on one’s progress and goal setting as well as the benefits of being active [45]. The South African adaptation process included a qualitative exploration with both health professionals and patients with stroke about their views relating to

Table 5.1 Explanation and application of the principles applied in Bridges Self-Management Program

Principle	Strategy
Problem-solving *Not being given solutions but encouraged to come up with ideas and strategies around issues*	Patient identifies issues of concern Guided to come up with solutions Given choices about what might help
Reflection *A key aspect is attributing changes and progress to personal effort/not skills of therapist*	Encourage reflection on changes made in past week(s) How they got there What strategies they used personally that helped
Goal setting *Two aspects; small steps for mastery experiences and longer-term aspirational goals* *Avoiding therapy-led goals*	Using a "liberated" form of goal setting (not necessarily SMART goals) Working with patients' ideas and hopes Encourage to break down goals into small steps if necessary Encourage to "think big" as well Encourage patient to capture change and progress with targets and bigger goals
Accessing resources *To use whatever resource is available to achieve personal goals – linked to social participation and community integration*	Link to goals and encourage patients to work out ways of getting support Working out ways of getting out in the community, planning together Using the internet/other resources to help Work out ways to use family and other supporters to help progress
Self-discovery *Finding out new ways of doing things, trying out different activities, so that any attempt to try and find a new way around something is seen as positive*	Noticing and discussing any changes, effort, activity Providing positive feedback for effort and doing activities (however small) independently Encouragement to use personal resources Encouraging use of past skills and strategies
Activity *Overlaps with self-discovery but focuses on encouraging any activity*	Encouraging ways to gain more activity during the day Building in exercises as part of normal routines Encouraging activities which increase endurance (physical, cognitive, and social) Design activity plan together
Knowledge *Knowledge not only about stroke but also about self.*	Tailoring information about stroke to individual needs Using open questions to determine current levels of knowledge Explore any potential barriers to behavioral change, e.g., fear about second stroke Explore ways of reestablishing important connections and activities, i.e., the key experiences that make people feel like their pre-stroke self

self-management. To develop locally relevant "stories" for inclusion in the workbook, individual interviews were also held with patients with stroke to explore their experiences [46]. Both health professionals and patients with stroke were provided with opportunities to engage with the workbook and provide their feedback. The participants reported the benefits of self-management as it related to patients' involvement and taking ownership of their recovery. The health professionals highlighted the need for training in the implementation of self-management. The importance of locally relevant "stories" was also highlighted by the South African participants [46].

Recommendations for Application of Self-Management Programs

Implementation of self-management programs within different settings and contexts is complex, and further feasibility studies are required to ensure that they align with cultural values and needs. In countries where access to healthcare is limited, self-management support could be explored as a strategy to facilitate greater social participation and community reintegration. This should, however, be accompanied by a review of behavioral changes needed by the health professionals, patients, and their family, as sharing expertise and working collaboratively can support self-management and reduce dependency. There are a number of outcomes that could be explored related to self-management. This includes, but is not limited to, the psychological impacts of stroke such as depression. Measurement of psychological aspects such as depression should therefore be included in future studies that explore the effects of self-management in stroke.

Future Directions

Rehabilitation professionals should explore self-management as a mechanism to apply patient-centered, goal-directed management of patients with stroke. Further research could be conducted to explore the effects of contextualized Bridges programs on stroke outcomes. As mentioned above, there are certain aspects (psychological) where the impact of self-management could be further explored.

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Chapter 6
Self-Management and Low Back Pain

Ina Diener

Introduction

Low back pain is one of the leading causes of disability worlwide [1, 2]. The literature has highlighted that persistent pain tends to be impacted by the intensity of the pain, the socioeconomic status of the patient, and the perceptions of the patient about their illness [3]. LBP as symptom is common in all age group and in almost all population in both developing and developed countries [4]. Healthcare systems are increasingly under pressure and financially unsustainable. The overall goal of a self-management (SM) program is to encourage patient responsibility to reduce the disability-related burden of musculoskeletal (MSK) pain for individuals and to lower the use of healthcare services.

Health, Social, and Economic Impact

In order to understand the disease burden, a Global Burden of Disease (GBD) study was carried out to assess the causes of the disease burden for the period 1990 to 2015 in various countries in order to provide a comprehensive assessment of patterns. LBP and neck pain, among others, lead the rankings in all age groups from adolescents to older adults, and are leading causes of years living with disability (YLD) [1]. In several high- to low-income countries, lower back and neck pain were the primary causes of disability and the primary drivers of YLD in those regions. LBP had an increase of 54% in YLD from 1990 to 2015. These cases accounted for

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77% of all disabilities reported [1]. Various studies have identified that the global burden of LBP will increase significantly in low- and middle-income countries [6, 7]. In order to combat this steady increase, there is a need to strengthen health systems that can focus on improving pain care and monitoring the incidence and prevalence of LBP [7]. The most common age group affected by LBP is the working age group, and workplace settings do not always accommodate the modifications that are needed to reduce the disability. In addition, LBP is also associated with risks such as depression, sleep disorders, anxiety, and stress sensitivity [6]. Consultations with general practitioners for back pain are common in primary health care. In a review of research into LBP trajectories, Kongsted [8] concluded that patients with LBP either recover rapidly or tend to develop chronic pain. The author also highlights the relationship between acute LBP and an ongoing chronic condition [8]. This highlights the need for management strategies that will allow patients to live with the condition.

Unfortunately, the literature highlights that levels of disability as a result of CLBP have still not been addressed adequately [1]. The associated impact of LBP on the health services should encourage health professionals and policy-makers to seriously consider how we address this challenge [3, 8]. Addressing these challenges may include but is not limited to effective individual self-management strategies.

The Clinical Picture of LBP

Triaging is advised in most LBP studies to determine the cause of LBP which may be known or unknown [1, 2]. The first level of triage includes ruling out red flags and serious spinal pathology (suggested as less than 1% of LBP presentations) and identifying neuropathic pain (5–10% of LBP) [9–11]. In the second level of triage, psychosocial distress is assessed and categorized. In order to classify patients with LBP into subgroups, Benecuik et al. [12] used the STarT Back Screening Tool (SBT). The classification was based on the presence of physical factors and/or modifiable psychosocial prognostic factors, to predict clinical outcomes. This also provided them with prognostic information for disability to influence important clinical decision-making for treatment monitoring.

Recurrences of LBP within 1 year are common and the literature commonly suggests that 33% of the patients with LBP will have a recurrence [13]. A meta-analysis [14] provides evidence that LBP can improve significantly within 6 weeks and have pain under control by 12 months. Understanding the risk factors and triggers for LBP is key to effectively managing the condition [2, 3, 14]. These factors should thus be assessed and addressed in a self-management support program. When considering this self-management program, the biopsychosocial model is a framework that can guide the design of the program as LBP is complex to manage. Factors that contribute to disabling LBP include the biophysical, psychological, social, genetic factors, and comorbidities. Information from developed countries currently guide our decision-making with less information from low- and middle-income countries; however, it is evident that there are multifactorial contributors to LBP that need to be addressed [5–7].

It is paramount that the clinician has a thorough knowledge and understanding of contemporary pain neuroscience. A few key concepts that have shifted our understanding of pain are summarized by Parker and Madden [15]. *First*, pain is not a signal that originates from bodily tissues; rather, pain is a perceptual experience that seems to be generated on the basis of a perceived need to protect bodily tissue from harm. *Second*, pain is not merely an indicator of tissue state, but just one somatosensory signal, and afferent signaling from peripheral tissues is subject to modulation at multiple points along its route to the brain. *Third*, the plasticity of the nervous system supports a reversal of sensitization processes and represents a viable target for treatment. If a patient understands that pain seems to be a protective drive, clinicians can identify the potential contributors to that protective drive [16]. Various factors influence how patients understand pain and these include but may not be limited to stress, perceived injustice, fear, and anger [17]. Psychosocial risk factor screening early in the course of LBP has been suggested for identifying patients who may be at risk for poor clinical outcomes.

As we consider the biopsychosocial model to address the management of chronic LBP, we need to integrate both biomedical and cognitive-behavioral principles [18]. Screening methods thus range from using full-length specific psychological measures (pain-related fear of movement, catastrophic thoughts, post-traumatic stress, anxiety, etc.) to brief risk prediction instruments such as the 9-item STarT Back Screening Tool [12, 19, 20]. The clinical picture of the patient with LBP needs to be seen in terms of the current pain mechanism at work (nociceptive, neuropathic, nociplastic) and the affecting psychosocial influences. These should be assessed within a strong therapeutic relationship, with effective clinical communication, applicable patient-completed outcome measures, and empirical stratification toward the most appropriate intervention during the support program for SM. The challenge of integrating these components may be an important factor in the evidence-practice gap [21, 22].

Current Approaches in Non-pharmacological Conservative Management of Chronic Low Back Pain

As we consider non-pharmacological intervention to manage chronic low back pain, we need to consider factors such as pain, function, self-perceived limitations, coping, and societal circumstances. We also need to consider an individual's capacity to take control of their own health and cope with changing life circumstances may be difficult [2]. The provision of inappropriate medical investigations and poorly evidenced passive healthcare strategies are potential reasons that the burden of persistent LBP is expected to rise in many countries in the next decade [22, 23]. Three fields of non-pharmacological conservative care for chronic LBP (CLBP) have received much attention in research studies in recent years which include manual therapy, exercise therapy, and education.

Passive Joint, Muscle, and/or Neural Mobilization

Nearly all types of manual therapy (joint and soft tissue mobilization, massage, myofascial release) elicit a neurophysiological response [24]. Manual therapy had an immediate analgesic effect on chronic LBP, and followed by specific active exercises, it reduced functional disability significantly with a larger decrease in pain intensity among patients receiving manual therapy than among controls who received only exercise therapy [25]. In a review on best-practice for chronic LBP, it was advised that pain neuroscience education and exercise therapy should be considered alongside passive joint/soft tissue mobilization and electrotherapy for CLBP management [26].

Exercise Therapy and Rehabilitation

Exercise interventions are recommended from many studies on CLBP. In an attempt to maintain positive long-term effects, cognitive behavioral techniques should be combined with exercise and psychological interventions [27]. Activity limitations are key among people with low back pain and may lead to an inactive lifestyle. Thus, it is essential that exercise forms part of a self-management program for back pain [28].

Education

Education has gained prominence in the research literature in recent years in two fields of information. *First*, communication should cover known trajectories of CLBP, the advantages of staying active, prognosis, unnecessary interventions, and the principles of intervention [2, 8, 29]. All information and discussion should be mindful not to increase pain-related fear, catastrophic thoughts, and anxiety [18, 30]. *Second*, education on pain neuroscience is key if we want to educate patients on knowledge about pain and demystify the threat associated with pain and thus conceptualize a patient's belief about pain [31]. Knowledge of pain has been demonstrated to facilitate a positive non-fearful experience with movement and exercise, thereby changing back pain beliefs and unrealistic expectations. Systematic reviews suggest that education on pain neurophysiology improves pain and physical, psychological and social function, reduces sick leave and healthcare utilization, and provides long-term reassurance for patients [31, 32]. Thus, including pain education into the management of patients receiving physiotherapy interventions is more effective [33]. All of these are intended to support a patient's engagement with self-management (SM) strategies [23, 27].

Including education of patients on back pain and its causes and the importance of remaining active is recommended as part of clinical guidelines. In a review of three recent major guidelines in 2016, the authors concluded that clinical guidelines exist to improve the burden of LBP-related disability and to reduce the use of low-value interventions [34]. In a 2018 review of clinical practice guidelines for the management of NSLBP [35], the authors noted that for CLBP, the guidelines recommend a combination of NSAIDs and antidepressants, exercise therapy, and psychosocial interventions. Despite existing guidelines, non-evidence-based practice strategies are commonly used for patients with CLBP [23]. As we deal with patients with CLBP, clinicians need to address all the components and integrate the important factors to close the evidence-practice gap. Thus, if we aim to successfully implement guidelines, there needs to be consensus between the clinician and the patient and thus reduce the variations in the management of patients with CLBP [22, 23]. Since 2018, there have been efforts by leading back pain researchers to reframe care for musculoskeletal pain, including CLBP [2, 22, 23, 26]. The current best-practice for individuals with chronic LBP thus seems to be in a package of care, of which a few combinations have demonstrated good outcomes, and may inform support programs for SM.

Cognitive Behavioral Therapy (CBT)

A systematic review and meta-analysis demonstrated that cognitive behavioral interventions can yield long-term improvements in pain, disability, and quality of life for patients with LBP of any duration and of any age [36]. Cognitive behavioral therapy can also be used effectively to address risk factors and can improve beliefs, pain, disability, and quality of life [37]. The CBT approach may facilitate an SM program.

Cognitive Functional Therapy

Cognitive Functional Therapy (CFT) involves the integration of behavioral psychology and neuroscience within physiotherapy practice. This flexible integrated behavioral approach aims to provide individualized care for people with disabling

LBP. The use of CFT is based on clinical reasoning and aims to identify and target modifiable factors that drive pain and pain-related distress [38, 39]. CFT has a strong component of behavioral change in physical activity.

Pain Neuroscience Education Combined with Exercise Rehabilitation and/or Manual Therapy: Cognitive-Targeted Exercise

A systematic review of pain neuroscience education (PNE) highlights that the combination of PNE with movement may be crucial to the success of using PNE as an intervention [31]. It is very important to reconcile the message of PNE (pain does not mean harm) with the message of correctional exercise and other physiotherapy techniques where pain may be a guiding factor for the treatment. This will avoid sharing potential conflicting messages to the patient [40]. In a study by Pardo [41], PNE combined with therapeutic exercise was effective in reducing pain, disability, and pain catastrophizing, compared to exercise alone in patients with CLBP. In a recent study combining PNE and cognition-targeted motor control training (CTMCT), results demonstrated reduced chronic spinal pain and improved function [42]. Any support program for SM of LBP should include PNE to facilitate self-exercise.

In Summary

As CLBP is a complex disorder, a structured but flexible clinical framework is needed to assess an individual's multidimensional characteristics and thus inform clinical reasoning about the relative weighting of modifiable factors as targets for individualized interventions [43]. In a review of clinical guidelines for LBP in 2016, there were consistent recommendations across three of the guidelines [34]: (1) advice against bed rest as a treatment option; (2) application of multi-modal care options, including exercise and education; and (3) inclusion of SM principles and psychological approaches in the management of pain-related symptoms. In a 2018 Lancet series, LBP was identified as a major global challenge and highlighted that there needs to be a reduction in low-value care that is ineffective or potentially harmful and advocated for high-value guideline-based care to be implemented [2, 22, 23]. A literature review in 2020 [26] identified consistent recommendations for best practice care across musculoskeletal (MSK) pain conditions, including patient-centered care, triaging and stratifying, thorough physical examination, evaluation of progress, education, and facilitation of movement/activity/exercises.

Self-Management as an Intervention for Chronic Low Back Pain

Healthcare systems globally are facing great challenges [2, 7]. To address these challenges, the inclusion of patient-centered care is highlighted. Self-management (SM) is defined as an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition [44]. The overall goal of an SM support program in managing LBP can be used to assist reducing LBP-related burden for individuals and for society, by improving patient SM and reducing the use of healthcare services.

Many LBP treatment guidelines [34, 35] emphasize the use of SM for LBP with the assumption that these approaches are beneficial for patients with LBP, but the evidence from outcome studies are not very strong. Several reviews highlighted small to moderate effects on pain and disability in people with LBP [45, 46]. A Cochrane review in 2014 concluded that there is low- to moderate-quality evidence that SM education programs resulted in small benefits in people with osteoarthritis [47]. A more recent systematic review and meta-analysis demonstrated that SM interventions only have marginal benefit for patients with chronic musculoskeletal pain [48]. Furthermore, no long-term effect of a SM support program was found in comparison to a low-impact physical activity intervention for individuals with chronic pain in general [49]. Up to 2018, the outcomes reported for SM programs for CLBP have not been promising.

In more recent years, however, a new type of SM support program has been developed, incorporating the latest evidence on how to best manage chronic musculoskeletal pain. A group of researchers in Denmark has formulated the GLA:D® program for SM support which consists of a two-day course that trains clinicians to deliver GLA:D® and a standardized evidence-based program for knee and hip pain [50]. The GLA:D® knee and hip program includes two sessions of patient education and twelve sessions of supervised exercise therapy aimed at teaching patients to self-manage their pain and functional limitations. The impact of the program led to a 27% decrease in pain, improved function, and decreased dependency on painkillers, and less people were on sick leave. The group has now also developed an evidence-based SM support program for CLBP [28] with the aim to provide patients with knowledge about LBP, skills in pain management strategies, specific back exercises, and exploring variation in movement. Primarily, it aims to change the patient's beliefs and behaviors by providing clear explanations and to promote confidence to move and participate in physical activities. All of these are intended to support a patient's engagement with SM strategies [28].

Another recent study reported on a far less comprehensive SM support program (pain science education and exercise) for patients with chronic pain [51]. This program was called the COMMENCE program and effectively improved the participant's function, pain, catastrophic thinking, self-efficacy, pain knowledge, satisfaction, and perceived change [51].

Competencies Needed for Self-Management Support Programs

Accepting SM of MSK pain is in principle a behavioral change that should happen in an individual. The definition of SM is limited in identifying how behavioral adjustment should be achieved and thus allows for a large variety of content and delivery modes in SM interventions. In 2014, Mann et al. conducted a review of approaches to SM interventions [52]. The results suggested that SM interventions contributed to decreasing reliance on healthcare services and reduced both the physical and psychosocial burden on affected individuals. In order to successfully implement SM interventions that can make a difference, healthcare professionals will need training on how to collaborate with their patients/clients in setting health goals and decision-making. They also concluded that SM interventions need tailoring to individual barriers, facilitators, and needs. The patient needs assistance to identify their own barriers and goals and may need information on how to identify optimal strategies to reduce or avoid symptom exacerbation and support to identify ways to measure the effectiveness of their SM efforts. As we promote a person-centered approach to self-management, it is important to provide a management plan rather than a cure for CLBP. Self-management support programs following these principles can be effective in improving the outcomes of SM programs in chronic pain groups. Furthermore, behavioral counseling may help to increase adherence to the program, and boosting self-efficacy may facilitate a positive lifestyle change [53]. Stenner et al. [54] explored the subjective dimension of SM by looking at the viewpoints of experts. The four factors were, *first*, change of mind-set; *second*, a patient-specific program; *third*, managing uncertainty; and *last*, support from the therapist. These four factors should guide the SM support provided, including the best techniques to change "mind-set" and "attitudes." Self-management is as much about changing how one thinks as it is about changing what one does, and successful SM means that as a patient you have control over managing your condition and relying less on health professionals. However, access to health professionals and knowing when to ask for professional help from time to time are needed to sustain the program [54].

Competencies of Participants Which Would Facilitate and Sustain Successful Self-Management

Individuals often encounter barriers to SM that need to be first assessed and then addressed in SM support programs, to assist them to succeed with SM. Thus understanding interventions to overcome the barriers is important.

Reconceptualization of Their Pain

Pain Neuroscience Education (PNE) aims to reconceptualize patients' beliefs about pain, to increase their knowledge of pain, and to decrease its threat. Individuals must understand and accept these pain principles and the chronic nature of their pain before they will be receptive to SM support [15, 31, 33].

Readiness for Change

Patients included in an SM program before they are ready for change in behavior may fail to change their behavior and thus not succeed in an SM program. The study of Katz et al. [55] demonstrates the importance of a potential pre-program targeted intervention for better patient engagement in an interdisciplinary pain program. The Pain Stages of Change (pre-contemplation, contemplation, action, and maintenance) Questionnaire [56] can be a useful tool to help identify how ready a person is for SM of their LBP.

Health Locus of Control

As we embrace the concept of self-management, we need to accept that each case is different and thus their health locus of control differs. Health locus of control (HLOC) generally refers to the extent to which individuals believe they can control events affecting themselves, in this case their LBP. You may determine a person's locus as with internal or external. The internal locus is conceptualized that the person can influence their own life situation and an external locus emphasizes that environmental factors influence their situation. Wahl et al. [57] found that higher levels of internal HLOC were related to better SM competency. The literature highlighted that patients with a high internal HLOC reached a greater reduction in pain intensity after treatment compared to patients with low internal HLOC [58].

Patient Activation

The patient activation level of healthcare is defined as the knowledge, skill, and confidence to manage one's health and healthcare [59]. It is important that patients have a clear understanding of their role in the care process and more importantly they should feel capable of fulfilling their identified role [60]. This is commonly measured by the Patient Activation Measure [60]. By not realizing that a patient has low patient activation (PA), they are set up for failure in SM. In a Swedish study on patients' preferences for physiotherapy, the overarching factor was active engagement in therapy, fostered by trust in the physiotherapist's competence and patient participation in clinical decision-making [61].

Competencies of Clinicians Providing Self-Management Support Programs

A holistic patient-centered approach by the healthcare provider is one comprising the three roles of educator, partner, and coach [62]. Healthcare providers need to fulfill these roles to foster adherence to a successful SM support program. Physiotherapists are in a unique role to implement SM support programs and should seek further training in the concept [62, 63].

Therapeutic Relationship and Listening Skills

A strong therapeutic alliance between the clinician and the patient can have a positive effect on the outcomes of an SM program. Understanding the needs of the client is key to promoting a change in behavior. Patient concerns are often voiced in an unstructured way. Clinicians need effective communication skills to elicit "what matters to patients," as meaningful conversations may encourage an active role for patients in their care [63, 64]. This may be better established with motivational interviewing, a patient-centered communication style for eliciting and enhancing motivation for behavioral change [65]. Patient-centered care is key to a biopsychosocial approach and is identified as personal, responsive, and fulfilling communication between patients and clinicians [65]. Communication factors valuing patient autonomy were identified by Oliveira et al. [66], demonstrating that in order to promote adherence to self-management programs, there needs to be good communication between health providers and patients. A therapeutic alliance describes the relationship between a clinician and a patient, based on respect and trust [62]. Communication skills training may enhance patient outcomes, and it needs to be a priority for effective SM support programs.

Awareness and Knowledge of Psychosocial Contributions to Pain and the Risk of Chronification

Screening for recommended psychosocial risk factors (*aka* yellow flags) that may be barriers to recovery has been researched abundantly in recent years. Screening for fear of pain, catastrophization, anxiety, post-traumatic stress, and other factors may be important in successful initiation of an SM support program [15, 19, 21, 23, 38, 53].

Ability to Do a Thorough Musculoskeletal Physical Examination

Pain should never be accepted as chronic pain with no apparent physical reason before a thorough questioning and physical examination to clear all red flags has been executed. Then only can a patient possibly be convinced that SM of their pain is an option [9–11, 64].

Knowledge of Evidence-Based Information

Changing behavior toward SM of pain needs patient education on several aspects. Clinicians need to have knowledge of the different trajectories of LBP [3, 8, 13, 14]; the natural path of chronic pain [67]; the evidence base for radiological imaging and the negative effect of unnecessary scanning [68–71]; evidence-based functional advice; and why exercise/activity is helpful [72–77]. This information should always follow the principles of contemporary pain neuroscience, not to increase pain-related fear [33, 72].

Pain Knowledge

The therapist should have a good understanding of contemporary pain neuroscience and external/internal influences on the experience of pain [2, 15–17, 31–33, 72]. This will assist to facilitate reconceptualization of pain by the participants, which is needed to change behavior in healthcare seeking and physical activity levels.

Person-Centered Care

A person-centered approach has placed it at the core of healthcare for people living with long-term conditions [78]. Patient-centeredness, from the perspective of CLBP patients, is a complex combination of six dimensions [79]: communication (listening), individual care (patient-as-person), decision-making (sharing power and responsibility), information sharing (education and advice), the clinician (clinician-as-person), and organization of care (access to and the amount of care). Effective communication is common to all dimensions.

Shared Decision-Making and Goal Setting

Shared decision-making is integral to high-quality, evidence-based, and patient-centered healthcare practice and needs clinicians to have skills and knowledge in both evidence-based practice and communication [63, 64]. SM will rather be accepted if decisions on the goals of care were taken jointly. However, shared decision-making is challenging. The literature highlights that key problems that emerge include but are not limited to power inequalities and the lack of the right attitude to share power and responsibility from both sides which may impede optimal participation [80]. As we encourage patients to participate in the management of their conditions, we should provide them with the skills to set goals, make decisions, and exercise training. Patients have diverse preferences in relation to participation in rehabilitation [81]. Shared decision-making enables a clinician and patient to jointly decide on the plan of action for the patient taking into consideration the patients values and preferences [18, 82]. The literature has highlighted interventions where patient-led goal setting was proven to be more effective in improving outcomes related to disability, pain intensity, quality of life, self-efficacy, and kinesiophobia in CLBP and can be maintained even at 12 months [83].

Knowledge of Patient Competencies Needed for SM and Barriers to Adherence to the SM Support Program

Clinicians should be well aware of barriers to behavioral change toward SM as this will influence patient adherence and successful outcomes.

Effective Rehabilitation

Effective rehabilitation is a person-centered process, with treatment tailored to the individual patient's needs and, importantly, personalized monitoring of changes associated with intervention [83]. An initial comprehensive (holistic) assessment to understand the patient's situation is of vital importance. Rehabilitation, based on the biopsychosocial model of illness, using many different interventions tailored to the particular patient, and monitoring changes, is characteristic of effective rehabilitation, and will contribute toward successful SM of back pain [24, 71–76].

Adherence to Self-Management Programs

Adherence could be a problem in that a noticeable number of patients are not adherent to interventions [85]. In a systematic review, Peek et al. [86] identified factors to aid patient adherence. These strategies include activity monitoring and an effective feedback system. In addition, exercise should be in a written format and the therapist and patient should set goals collectively. Combining interventions and tailoring them to the specific needs of individual patients rather than a group of patients may also improve adherence [57, 66, 71, 78].

An Evidence-Based Program to Prepare Patients with Chronic Low Back Pain for Self-Management

Education and Advice

A Delphi study of experts' opinions on advice for people with LBP identified crucial messages for patients with LBP [87]. This list of crucial messages can be used to inform the development of education resources (websites and other educational material) for support of patients self-managing their LBP.

Exercises and Activity Rehabilitation

Wade [84] recently summarized the essence of rehabilitation by stating that the end-goal of rehabilitation is to optimize a patient's self-rated quality of life and degree of social integration. This can be achieved through optimizing independence, minimizing pain and distress, and optimizing the ability to adapt and respond to changes in circumstances. Person-centered care and shared decision-making will facilitate adherence to exercises [85, 86]. In many cases of chronic LBP, patients dissatisfied with the care of multiple practitioners they have consulted for treatment must be convinced to take care of themselves. The path between LBP guidelines and person-centered care is difficult to navigate in clinical practice. In many cases, it is only necessary to get individuals back to doing simple ADL or their favored activity. Smith et al. [74] challenged existing paradigms for musculoskeletal pain and exercise and suggested targeting pain-related fear through exercise. To be able to reconceptualize this fear of movement of individuals with CLBP, they suggested that healthcare providers should understand what the patient understands, challenge these unhelpful beliefs, enhance self-efficacy, provide safety clues, provide advice on suitable levels of pain, and provide advice on exercise modification. Pain neuroscience education (PNE) could serve as a preparation for graded exposure to activity and exercise.

Combination Programs

Prevention strategies to reduce future impact of LBP demonstrated moderate-quality evidence indicating that an exercise program can reduce short-term future LBP intensity and that exercise combined with education can reduce future disability due to LBP at long-term follow-up [87, 88]. Various studies have highlighted that combination programs are successful [28, 42]. In summary, self-management is a safe, community-based and effective way for patients with chronic LBP to manage pain and disability. Core skills of SM should be delivered in support programs, using multiple approaches. Successful implementation of SM support programs requires patients to change unhealthy behaviors and commit to healthier ones, but changing individuals' behavior is challenging. Therefore, it is important to assess patients' knowledge of SM support, skills, and confidence in managing their own health. Effective implementation of SM support programs also depends on the skills of service providers, of which communication skills training seems to be the most important, to understand the individual and the barriers that may be faced when using SM in chronic LBP [78–80, 87].

Future Directions

An analysis of the current epidemiology published in 2020 demonstrates that LBP could be classified as a primary healthcare issue [89]. This evidence highlights the need for additional efforts on prevention and care of LBP by increasing public funding on research, by improving public awareness on the clinical, psychological, societal, and economic consequence of living with LBP, and by developing new SM support programs of education and rehabilitation that would satisfy individuals with CLBP and decrease healthcare usage.

Even though the Lancet LBP series [2, 23, 24] in 2018 reviewed an evidence-based restructuring of care for persons with LBP, it is doubtful that this new direction has been implemented by the majority of healthcare providers in the field. Research studies and reviews published from 2018 to 2020 have proposed improved interventions, based on a patient-centered approach and applied with contemporary pain neuroscience in mind. It is, however, very likely that the LBP SM support programs published since 2018 have only been implemented by a minority of healthcare providers.

Entry-level education needs to change by embedding psychosocial perspectives within physiotherapy practice for patients with LBP and the opportunities that could be realized by doing so [90, 91]. Healthcare providers working with patients with CLBP should be up-skilled to be in line with the latest pain and psychosocial research literature. Moreover, communication skills training needs to be a priority for effective SM support programs.

Research into SM support programs for CLBP needs to include not only its biological and psychosocial components but also how these components influence one another. Langevin [92] argues a good case for reconnecting the brain and the body in future research. A challenge in understanding chronic musculoskeletal pain is that research often addresses various aspects like neuroscience, physical therapy/rehabilitation, orthopedics, and rheumatology in silos. Although these disciplines individually study important aspects of pain, there is a need for more cross-disciplinary research that can bridge brain function and behavior, behavior and tissue structure, musculoskeletal and immune systems, and peripheral tissues and the nervous system.

The community needs to be educated. Keeffe et al. [93] provide four aspects of accessible, engaging, and convincing education to the public and health professionals: mass media campaigns, taking note of new findings in research, learning from other fields, and integration of new media. It is important that as clinicians we provide our clients with evidence-informed information to manage their LBP. Chalmers and Madden argue that community education to shift beliefs would truly lay the foundation for biopsychosocial care [94]. Pain information websites and programs can be very helpful to patients in pain.

Although the current evidence base for effectiveness of SM programs is not strong [45–49], there is evidence that application of new knowledge of pain neuroscience and clinical communication skills may improve adherence to exercise rehabilitation programs. A few promising study outcomes and proposals for SM support programs for CLBP have been published [28, 42, 51]. Some reasons why generic SM interventions may not be effective is that behavior change is not easy, SM support programs are too variable in content and delivery, and there is limited and inconsistent application of behavioral change theory throughout interventions [53]. Healthcare professionals, including physicians, nurses, physiotherapists, occupational therapists, psychologists, etc., need to be trained in the skills of facilitating behavioral change toward SM. Future studies should investigate the interaction between SM skill training and LBP treatment components and include more tightly structured treatments to improve consistency of interventions.

Conclusion

In conclusion, clinicians should examine and characterize individual's multidimensional characteristics and consider the relative weighting of *modifiable factors* as targets for individualized support programs for SM [38]. In order to be effective in providing holistic care, we may have to upskill clinicians as an integrated approach to managing CLBP may lead to improved treatment outcomes. Although there are several global initiatives to address the global burden of CLBP as a public health problem, there is a need to identify cost-effective and context-specific strategies for managing CLBP to reduce the consequences of the current burden. SM support programs are seen as one of the possibilities to reduce the healthcare burden of

LBP. Clinicians have a collective responsibility to educate patients, the community, funders, policy–makers, and other clinicians on SM to help reduce the disability and cost burden in society.

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Part III
Using Self-Management Across the Lifespan and Across Settings

Chapter 7
Self-Management in Youth

Lisa Wegner and Wilson Majee

Introduction

Youth, through their natural energy and creativity, have the potential to play a major role in society as contributing citizens and change agents. Society needs to harness this potential and promote youth engagement in ways that enable young people to make meaningful contributions. One way to do this is by developing and supporting self-management in youth. Youth who have the capacity and skills needed to manage themselves are far better equipped to deal with the challenges they face in a rapidly changing world. The fourth industrial revolution and the era of digitalization, in conjunction with the recent COVID-19 pandemic, which left no country unscathed, have highlighted global inequalities and spawned a complex array of new challenges that youth need to manage in order to survive and thrive. According to the World Economic Forum, the ten most crucial skills needed to thrive in the fourth industrial revolution are complex problem-solving, critical thinking, creativity, people management, coordinating with others, emotional intelligence, judgment and decision-making, service orientation, negotiation, and cognitive flexibility [1]. Self-management is an integral component for all of these skills.

The purpose of this chapter is to describe the social-ecological challenges that youth face and explain their influence on self-management, and discuss how to

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promote self-management in youth through the use of guidelines, strategies, and principles for planning self-management programs. This chapter offers a different perspective from previous literature, which has focused predominantly on medical self-management programs for young people living with a chronic condition or with special health care needs [2].

The United Nations defines youth as a group of people between the ages of 15 and 24 years. We use the term "youth" more broadly to refer to the period of transition from the dependence of childhood to the independence of adulthood, with an accompanying awareness of interdependence within communities [3]. Youth need to negotiate four major interconnected life transitions, namely, continuing to learn, starting to work, exercising citizenship, and developing a healthy lifestyle [3]. These transitions require youth to take responsibility and utilize self-management skills. However, each transition confronts the youth with diverse challenges, depending on the context in which they live, that need to be overcome.

In 2019, the world was home to 1.2 billion youths aged 15–24 years, most of whom lived in low- to middle-income countries (LMICs): Central and Southern Asia (361 million), Eastern and South-Eastern Asia (307 million), and sub-Saharan Africa (211 million) [4]. As child survival rates continue to improve, the number of youths in the world is projected to grow by 7 percent to 1.3 billion by 2030 [4]. Notably, in LMICs, the youth population is projected to increase by 62 percent, with largest increases expected in sub-Saharan Africa (+89 percent), Oceania (+38 percent), and Northern Africa and Western Asia (+28 percent) [4].

Unfortunately, one-fifth of the world's young people currently are neither in education, employment, or training, which is known as NEET status [5]. The labor force participation rate of young people (aged 15–24 years) has continued to decline over a period of 20 years from 568 million to 497 million [4]. Recent pandemics such as COVID-19 have further slowed economic activity. These developments are particularly detrimental to youth, particularly those already in NEET status as their employment prospects are more sensitive to economic downturns [5].

Challenges Faced by Youth

Although millions of dollars have been channeled toward creating opportunities to engage youth in community life, many youths remain disengaged and/or in NEET status [6]. Success in promoting youth engagement has not been remarkable on the whole as the threats and challenges to sustainable development, including unemployment, poor education participation, poverty, migration, and family breakdown, have persisted [4]. Globally, young people are growing up under complex economic conditions defined by high unemployment rates, limited school to work transition opportunities, widespread poverty, and weakening social norms [7].

Regarding employment, 71 million young people are unemployed, and millions more are in precarious or informal work positions. In the field of education, 142 million youth of upper secondary age are out of school [4]. For example, the June

2014 labor force survey reported that in South Africa alone, 36.1 percent of youths aged 15–35 years were unemployed [8]. Unemployment is especially high for young people living in rural areas, with youth unemployment rates above 70 percent in the Eastern Cape, South Africa [9]. Although progress has been made with institutionalizing youth development, concerns related to youth such as youth disengagement, unemployment, and family and community disintegration which existed pre-apartheid [10] have continued in the post-apartheid era in South Africa [11, 12]. High rates of grade repetition, school dropouts, and low participation rates in further education, particularly among black and colored youth, continued to exist in the post-apartheid era [11, 13]. Compared to trends in LMICs, in the USA, the number of young adults disconnected from both work and school fell from a recession-fueled high of 14.7 percent in 2010 to 11.2 percent in 2018. However, because of the current COVID-19 pandemic, it is projected that youth disconnection in the USA will spike from 4.5 million to over 6 million in 2020 [14]. The COVID-19 global pandemic and its economic and social impacts have disrupted all aspects of life for all groups of society. For youth, the COVID-19 crisis poses considerable engagement threats in education and employment. As in most other countries in the world, the COVID-19 pandemic is also expected to cause an increase in the number of youths in NEET status in South Africa. With the increase in online learning or working from home, and with youths physically disconnected from schools and workplaces, those with the fewest resources will face the highest re-engagement barriers [5] resulting in them being left even further behind.

Poor education leads to unemployment, which in turn may result in poverty – a major cause of disengagement. Poverty undermines parents' ability to provide the goods and services, for example, books and computers, necessary for their children's engagement in meaningful activities such as education and training. Furthermore, economic hardship can increase psychological distress and conflict in parents both of which may lead to harsh, inconsistent, and detached parenting [15]. For young people, poverty and its associated consequences such as deprivation, parental detachment, and hopelessness can provide fertile ground to engage in health risk behaviors. Globally, there are 429 million young workers, of whom about 55 million (13%) live in extreme poverty (defined as living on an income below US$1.90 per day), while 71 million of them, or 17 percent, live in moderate poverty (an income below US$3.20 per day) [5]. According to Statistics South Africa (2016), about 19 percent [10.5 million] of South Africa's population are youths between the ages of 15 and 24 years. In 2016, close to 62 percent of this age group lived in poor households, of whom 14 percent were in households with no piped water [9]. Only 25 percent lived with both parents and 29 percent of females aged 15–24 years had given birth to a child. Many of these youths also grow up in households where no adult was employed, thereby dampening employment prospects for young people [9].

Another challenge that today's youth faces is that of changing family structures and weakening familial norms. For example, in 2019, 53 percent of US adults aged 18 years and older were married. This went down from 58 percent in 1995. Over the same period, the share of Americans who were cohabiting rose from 3 percent to 7 percent [16]. Globally, most people cohabit at least once in their lives, and most of today's marriages are preceded by cohabitation [17, 18]. Furthermore, due to high divorce rates and increases in out-of-marriage childbearing, single-parent families have also become more common [17, 19]. These changes can influence the choices youths make in terms of their engagement in school, training and/or employment, and in other meaningful community activities.

The Influence of Challenges on Self-Management in Young Persons

Self-management emphasizes the expectations a person has about being able to achieve a specific behavior. This sense of self-efficacy influences success in initiating a new behavior [20]. Self-efficacy can be improved through strategies such as skills mastery, modeling, alternate explanations for physiological symptoms, and social persuasion [21]. In turn, mastery of a new behavior gives individuals more motivation and confidence to change other health behaviors [22]. Self-esteem has been described as an internal perception of one's self-worth or confidence in one's abilities to be able to cope with challenges posed by life [23]. A lack of self-esteem may result in the individual failing to adapt to the situation and therefore experiencing life as stressful and shameful [23]. Several factors may trigger feelings of shame in young people.

One of the situations is being unemployed and/or experiencing a failure to transition from education to training or to labor force participation and thus jeopardizing the transition to adulthood. This occurs as many of the youth face limited employment prospects, delay finishing school, postpone establishing their own households and starting families, and remain financially dependent. Although unstable employment histories are common among vulnerable youths in the early stages of their careers, unemployment threatens the ability to secure economic self-sufficiency and residential independence and has strong marital prospects – all of which are widely accepted markers of adulthood. Thus, being employed is important to one's identity, and societal attitudes sometimes associate unemployment with being lazy or not wanting to work, which brings feelings of shame. Unemployment has been reported to reduce young adults' self-efficacy [23]. This study concluded that unemployment could influence the young adult's confidence in two ways: first, by delaying or preventing successful transition to adulthood (e.g., economic self-sufficiency, marriage, parenthood), and second, by providing the opportunities for parental financial assistance that undercuts the youth's autonomy and independence [24]. Other researchers argue that the longer young people spend being NEET, the higher the risk of them having poor labor market outcomes in the longer term and that if young people find work after being NEET, they were more likely to get a job that does not provide opportunities for training [25–28]. Young people who fail to launch by their mid-to-late twenties may think they are less worthy, or even question their adulthood, which in turn can contribute to a lower self-esteem and capacity for self-management.

Unemployment, poverty, parental detachment, and changing family structures have far-reaching health, well-being, and self-management consequences for youth. Many youths who lack hope in their families and communities, and disengage, tend to lack purpose, indulge in activities that are detrimental to their health, and are more likely to require welfare support and government-subsidized services [29–31]. Studies suggest that disengaged youths are less self-reliant, lack a sense of purpose, and indulge in activities that are detrimental to their health [32, 33] such as substance use. Substance use remains an ongoing threat to health, affecting both LMICs and high-income countries [34]. Factors fostering and challenges associated with substance use vary significantly across regions and countries. Substance use in sub-Saharan Africa was found to be associated with specific sociodemographic factors such as poverty, male gender, and younger age [35–37]. Substance use becomes more complex in countries such as South Africa, where there is an increasing number of young people growing up in the context of multidimensional poverty. Substance use can have a severe and detrimental impact on overall health, and in many cases, the well-being of others. In young men aged 20–24 years old in South Africa, alcohol and illicit substance use are responsible for 14 percent of the total health burden in terms of financial cost, mortality, and morbidity associated with substance use [38]. In South Africa, it is estimated that up to 60 percent of the crimes committed involve the use of substances and 80 percent of male youth deaths are alcohol related. South Africa also has a fetal alcohol syndrome rate which is five times that of the USA [39].

In recent years, the use of substances such as nyaope and methamphetamine has become an increasing concern in South Africa. Nyaope, also known locally as "whoonga," is a mixture of low-grade heroin, cannabis products, antiretroviral drugs, and other materials added as bulking agents, which are usually added to marijuana and smoked. Nyaope is unique to South Africa and is used predominantly by young, unemployed people living in socioeconomically depressed areas [40]. The use of methamphetamine, also known as "tik" because of the popping sound it makes when heated, has also increased, particularly in the Western Cape. A study amongst 10,000 grade 8 learners in 54 schools in the Western Cape, South Africa, reported that approximately 5 percent of learners had used methamphetamine within their lifetime; of these users, 65 percent had used methamphetamine in the past month or week [41]. Youth living in rural communities, particularly in LMICs, are often marginalized by their geographical context in addition to other factors discussed earlier. In rural areas, youth disengagement is exacerbated by poverty; underdevelopment; poor or fragile economic, political, and resource governance; environmental degradation; and fragile social systems [42]. In South Africa, a study of risk behavior in rural youth, the majority of whom were aged 18–21 years old, found that just under half had dropped out of school before completing grade 12 [43]. Past month prevalence of substance use showed that 64 percent had used alcohol, 37.2 percent had used cannabis (dagga), and 8.9 percent had used methamphetamine [43]. Youths with high-risk conditions such as poverty and substance use tend to be more disconnected and typically lack trust in existing support systems [44].

Given the emerging global youth disengagement crisis, anticipated population growth, continued rural–urban and a cross-border migration pattern, and the current economic meltdown due to COVID-19, there is a growing need for evidence-based local and national programs and policies that promote engagement and self-management in youths.

Promoting Self-Management in Young People

Youth engagement has been defined as the participation of youths in responsible activities at family, institutional, and community levels [45]. Within the context of youth engagement, self-management has increasingly become a phenomenon of interest, as it develops and strengthens engagement and connectedness. Self-management in youths can be regarded as the readiness and capacity to take responsibility for oneself and engage constructively as active citizens, which ultimately enhances society and contributes to poverty reduction.

The social-ecological model, introduced in the 1970s, is a theoretical framework to understand the multifaceted and interactive effects of personal and environmental factors that govern behaviors [46–49]. These factors include individual (e.g., age, gender, income, and education), relationship (e.g., family and peers), community (e.g., schools, workplaces, and neighborhoods), societal (e.g., social and cultural norms), and policies. The social-ecological model provides a useful framework to guide activities that promote and support the development of self-management.

On an individual level, youths who have the capacity and skills for effective self-management will be better enabled and equipped to, for example, refuse drugs, insist on safe sexual behaviors, manage their mental health issues, make positive choices about careers and partners, and participate in healthy leisure activities. Family-level activities may include participation in family decision-making processes which improves self-esteem, responsibility, and social behaviors [50]. While there is no clear-cut distinction between institutional and community-level engagement, activities may include volunteerism [42, 51, 52], political engagement [53], and economic activity [54]. Creating opportunities for youth participation in these environments is therefore foundational toward promoting sustainable youth engagement [55]. Youth engagement can be strengthened through schools that facilitate teacher-student-community triad engagement [56]. At the community level, civic engagement is nurtured when youths take on organizational and/or community leadership roles [57, 58]. Unfortunately, youths who have dropped out of school are even more vulnerable, as they are unable to benefit from school-based programs and become disconnected from community organizations.

It is of vital importance that when promoting self-management, consideration is given to how vulnerable youths, such as out-of-school youths, can be facilitated to re-engage in society. A study that explored young men's perceptions and experiences of disengaging from gangs in Cape Town, South Africa, revealed the importance of supporting youth engagement in pro-social activities and projects that were meaningful and provided opportunities to connect with communities [59]. Examples of this include redeveloping community facilities by cleaning, fixing, or rebuilding the facilities for better use, sports coaching, and planning and running after-school leisure interventions.

In their study on family structure and youth engagement in the USA, Anakwe and colleagues noted that family has a strong influence on youth development and that the belief that structurally diverse families are broken creates an engagement difficulty for youth in structurally diverse homes [60]. In a related study on how youths and adults perceive and utilize shared community resources (e.g., the library and recreational amenities), Majee and Anakwe (2020) noted that there needed to be an alignment between community leaders' and youth's perceptions of community resources. If there was a lack of congruence in perceptions on shared resources, it would impact on how youth engage with adults [61]. It was reported that if this misalignment persists, youth become carriers of risk rather than contributors to the development of their communities [62]. Such a perception dilutes any motivation that young people may have to contribute to their communities and elevates the need for strong youth-adult partnerships that can support youths to become engaged and contributing members of society. Also, when adult perceptions and community programs fail to engage young people, it is easy to attribute that difficulty to the youths themselves, instead of assessing current attitudes, practices, and opportunity structures in the community to gauge the readiness of youth to engage.

Participation in leadership roles is one pathway to keep young people engaged at the community level [63]. In a study of rural South African youth on the perceptions of their future communities, researchers observed that youths who lived longer in the community had higher perceptions about the future of their communities compared to those that had not lived within the community as long. Motivation to participate in leadership roles was higher among those who perceived value in the community and young adult engagement resources provided at the local level. This study found that young people's participation in community leadership roles was strongly related to perceptions of how important the provision of key resources at the local level (particularly human, social, financial, and built capital) will contribute to their future community [64].

Guidelines, Strategies, and Principles for Planning Self-Management Programs

Useful guidelines for planning self-management programs for young people include the use of a social-ecological model perspective and the UNESCO Operational Strategy on Youth 2014–2021. The latter advocates for the application and promotion of (i) rights-based approaches, (ii) gender equality and non-discrimination, (iii) focus on reaching vulnerable and marginalized youth, (iv) youth participation in the development of initiatives affecting them, (v) intergenerational dialogue and youth-adult partnerships, and (vi) foresight and anticipation approaches [3].

Self-management takes place within a context of risk and protective factors depending on the individual and the physical and social environment. Adopting a social-ecological model perspective implies that self-management programs and activities should focus on building the capacity and skills of individuals to more effectively take control of their lives, develop relationships, be educated and find gainful employment, and engage in prosocial community and societal organizations. In addition, thought should be given to supporting and promoting policy issues related to youth, for example, advocating for job opportunities and creating learnerships for youths. Thus, it is important that program planners take into consideration the particular challenges within the context where the programs will take place. Self-management programs should aim at equipping the youth with skills to take responsibility for their own behavior and well-being. Various skills are required for self-management, including decision-making, problem-solving, judgment, insight, managing stress, self-confidence, emotional regulation, persistence, resilience, assertiveness, and communication. Supporting young people to develop self-management is a process of developing these skills and should be an integral component of all youth development programs.

Various other strategies can be used to support self-management including positive youth development, youth-adult partnerships, and youth participation, for example, in economic activities or skills-building programs that improve their chances of participating in the labor force. Implicit in positive youth development is that youths are seen as assets to their community, rather than deficits to be fixed [62, 65]. Therefore, the focus is on youth strengths, and program activities are designed to develop caring, confidence, competence, connection, and contribution, ultimately developing character [66]. The notion is that all youths possess a purpose and that each individual carries the capacity for positive development and therefore has the potential to reach a healthy and successful adulthood [66]. Vulnerable youths however, may need help to discover what their purpose is, and require opportunities to develop their purpose. The positive youth development approach affords confidence that all youths, when they are allowed the opportunity, are able to develop within the context of communities. When the strengths of youths are united with the assets of their community, this may foster positive development [66].

Aligned with positive youth development, the potential for change in systematic behavior is dependent on the developing persons, their biology, and many other contributing factors, such as culture, community, family, and school [66]. When programs include positive youth-adult relationships, skill building activities, and opportunities for youth leadership, such programs have a great potential to foster the development of these characteristics. Lerner and colleagues [65] explain that when youth are able to develop a mutually beneficial relationship with others and organizations of their social sphere, they will embark on an optimistic journey filled with positive influences for themselves, their families, and their communities. Youth programs should concentrate on enhancing the fit between the capacities of the youths and the resources for positive development that exist within their communities. In such a policy context, young people may thrive and society may prosper [66].

Youth-adult partnership is a strategy whereby adults provide the scaffold for the youth to build on and develop capacity. Thus, it is a useful empowerment strategy to support self-management programs. The increased interest in self-management among youth stems from a) the need to equip young people with skills that support them to become contributing community members, and b) the difficulties associated with keeping youths engaged, particularly in resource-limited settings. A study was conducted to develop a mobile health (mHealth) app to support young people in self-managing type 1 diabetes [67]. Findings showed the importance of using a participatory approach by including end-user groups (including young people and their parents) during all phases and establishing a multidisciplinary team to provide the wide range of expertise required to build an mHealth app. The same principles can be applied when developing programs that promote self-management in young people.

Youths, particularly those who are no longer in school and are not employed, often lack basic work and life skills, such as responsibility, time management, ownership, commitment, and appropriate social skills. Self-management programs should therefore aim to infuse the development and use of these skills in optimal ways throughout all aspects of the program. A number of principles that can guide the planning of self-management programs for youths exist. Wegner and Kasu (2018) used a participatory, positive youth development approach to develop a relevant intervention for out-of-school youths in Cape Town, South Africa. They found that incorporating positive reinforcement using peer pressure, program expectations, and setting rules in positive ways worked well [68]. Furthermore, youth participants recommended that programs should be activity-based and include having fun while learning. Youths should sign up or enroll themselves voluntarily for specific programs and commit to attending the program in full. Programs should be time-defined with set program schedules, for example, a 2-month performing arts program taking place once a week with a performance as an outcome. Youths should have a voice in program design and intervention. Programs should be monitored and evaluated, preferably by youths themselves. Clearly, adopting a participatory action approach is crucial in program development and implementation. Furthermore, a multi-sectoral, multi-systemic approach that includes partnerships with strategic stakeholders is essential to develop self-management, resilience, and engagement among vulnerable youths, such as those living in rural contexts [43]. Wegner and colleagues [43] provided an example of a youth-adult partnership to promote resilience in the youth in rural communities in South Africa. They suggested that corporates, such as local Wind Farms, could use their corporate social investment funding to assist youth to establish self-management programs in local communities. This could include the sourcing and setting up of suitable venues where the youth could meet safely and offer various programs, for example, the venue could house a coffee shop that could offer quality coffee and baked goods to the local community and visitors. Youths could learn to manage the coffee shop and bake, market, and sell affordable, quality home-baked goods. The coffee shop would also have free Wi-Fi, computers, and, if space allowed, a garden for growing vegetables and flowers for sale to the community. Such an endeavor offers fertile opportunities for the youth to develop self-management skills. However, in light of the lack of knowledge in this regard, further research needs to explore the feasibility and efficacy of such programs in developing self-management in young people.

Conclusion

Self-management in young people is influenced by a variety of socioecological factors and challenges ranging from the individual to policy-level considerations. With the anticipated youth global population growth, the need for collaboration at all social-ecological levels to support self-management in the youth cannot be overemphasized. In this chapter, we have outlined ideas to promote self-management among vulnerable youths that would equip them to manage challenges and reach their full potential. There is still a need, however, for further research that focuses on the implementation and evaluation of self-management programs with vulnerable youths.

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Chapter 8
Self-Management in Chronic Illness in the Elderly

Seyi L. Amosun

Introduction

The World Health Organization (WHO) acknowledges that "old age" begins from 60 years, a shift from 65 years that is still acknowledged in developed countries [1]. The Global Age Watch Index projected that there will be approximately 1.402 billion elderly persons in 2030 (16.5% of global population) and 2.092 billion in 2050 (21.5% of global population) [2]. The growth rate of population aging is higher in low- and middle-income countries (LICs; LMICs; MICs) than in high-income countries (HICs) [3]. In 2015, the life expectancy at age 60, which is the average number of years that an individual at a specific age is expected to live if age-specific mortality levels remains constant [4], ranges from 13 years in Sierra Leone, an LIC in Africa, to 26 years in Japan, a HIC. In many countries, life expectancy at 60 years is now at least a third more than what it was in the mid-twentieth century [2]. Therefore, population aging is seen "*as a success story for public health policies and for socioeconomic development, but it also challenges society to adapt, in order to maximise health and functional capacity of older people as well as their social participation and security*" [1].

However, the lived experiences of elderly persons depend largely on where they live and their circumstances earlier in life. For example, the generations of elderly persons in Africa in the twentieth century were those who experienced poor education, were undernourished as children, and suffered numerous infectious diseases [5]. The global projected increase in the number of elderly persons thus raises serious public health concerns in view of socioeconomic challenges, coupled with high disease burden in LIC [2]. In addition, because of the vulnerability and

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frailty that are associated with aging, the proportion of the elderly with multimorbidity of chronic conditions, defined as the coexistence of two or more chronic conditions that require ongoing medical care or monitoring, has increased globally [6–9]. Factors associated with multimorbidity in elderly people included smoking, alcohol consumption, living in rural areas, low levels of schooling, the female gender, age, living alone, polypharmacy, and a negative self-perception of health. The consequences include greater risks of death and functional decline and increased vulnerability to pandemics [10].

The healthy life expectancy at 60 years is the average number of years that a person can expect to live in "full health" by considering years lived in less than full health due to disease and/or injury [4]. In 2015, it ranged from 9.3 years in Afghanistan (another LIC) to 20.3 years in Japan. Responding to the growing number of the elderly, the global active aging policy framework was developed to improve the quality of life of aging individuals [1], focusing on three major goals, namely elderly persons and development; advancing health and well-being as individuals transition into old age; and ensuring an enabling and supportive environment. A number of determinants of active aging were identified by the framework. These include behavioral styles, personal biological and psychological conditions, health and social services, physical environment, and social and economic factors [11]. Although these determinants are different depending on contexts and cultures, they can be used to inform community-based and individually based interventions as they contribute to the three key components of active aging, namely autonomy, independence, and quality of life. For the purpose of this write up, it is within the WHO active aging framework that the self-management of chronic conditions in the elderly is addressed.

Concept of Self-Management of Chronic Conditions

The prevention treatment and management of chronic illness is gaining increased recognition as a public health concern [12]. Its management is a complex process which is further complicated by multimorbidity. The challenges with healthcare provision in many countries highlight the need for individuals with chronic conditions to care of themselves [13]. While there may be multiple definitions for self-management that are disease specific, there are certain common conceptual dimensions [13–16]. Broadly defined, the process requires that the clients and healthcare providers engage collaboratively to assist clients take control of managing their own care [9, 16]. The process also emphasizes choosing proper treatment options, making health-related lifestyle changes, monitoring and managing signs and symptoms of the illness and treatment, and compensating for physical and social consequences of the illness [15]. The following characteristics are common: (a) earmarking financial resources for chronic disease management, (b) obtaining health- and disease-related education, (c) making use of ongoing social supports, (d) responding positively to health changes, (e) continuing interaction with the health system, and (f) actively participating in sustained disease management [9]. However, it should be noted that the process entails what the patient does to manage the illness, not what the healthcare professional does with or for the patient.

Community-based self-management program is an example of a population-based approach used to address chronic conditions globally [12, 13, 17]. However, the literature is lacking that specifically conceptualizes the aspects of self-management in elderly individuals with multiple chronic conditions [9].

Burden of Chronic Conditions Multimorbidity in Elderly Persons

The prevalence of chronic conditions in elderly persons in HICs is presented in Table 8.1. The data are extracted from a pattern observed from 52 studies selected for a systematic review that involved more than 60 million elderly persons in 30 countries [18]. Within the age groups of 65–74 years, 75–84 years, and ≥ 85 years, the reported prevalences of multimorbidity were, respectively, 62.0%, 71.7%, and 78.0%. Table 8.2 presents data about chronic conditions in elderly people from MICs and LICs [19]. Data about chronic conditions and multimorbidity in elderly persons ($n = 23{,}838$ aged ≥65 years) from 46 LICs and MICs were extracted from a larger study that investigated the relationship between chronic conditions and low physical activity among 2280 community-dwelling adults aged ≥18 years in 70 countries worldwide. These global trends prompt greater investment in rehabilitation services which are integrated in the five core components of the community-based rehabilitation matrix and their key elements [20].

Table 8.1 Prevalence of chronic conditions in high-income countries [18]

Chronic conditions	Prevalence (%)
Hypertension	60.6
Dyslipidemia	51.2
Pain disorders	34.0
Diabetes	25.2
Arthritis	23.4
Anemia	22.8
Ischemic heart disease	20.3
Thyroid disease	16.0
Renal disease	14.9
Anxiety	14.5
Heart failure	14.0
Chronic obstructive pulmonary disease/asthma	12.8
Depression	12.0
Osteoporosis	9.8
Stroke	9.4
Cancer	8.6
Dementia	8.4
Parkinson’s disease	3.2

Table 8.2 Chronic conditions among people ≥65 years in low- and middle-income countries [19]

Chronic conditions	Prevalence (%)
Angina	32.5
Arthritis	33.3
Asthma	9.6
Chronic back pain	16.6
Diabetes	9.0
Edentulism	28.9
Hearing problem	20.0
Tuberculosis	2.6
Visual impairment	6.4
Number of chronic conditions – multimorbidity	
0	25.1
1	28.2
2	23.5
3	14.0
≥4	9.2

Conditions such as heart disease, cancer, stroke, and diabetes are major causes of death in the elderly. These conditions are also associated with functional disabilities and decreased quality of life in this population [21]. The healthcare cost of managing these conditions is considered high in HICs. The burden of chronic conditions in elderly persons living in LICs, LMICs, and MICs is disproportionate to those living in HICs. These individuals also experience significant disparities in accessing aspects of primary healthcare services as a result of socioeconomic, behavioral, and other factors. Given the effect of normal aging processes on functional capacity, which may compromise their safety in these countries [22], self-management may be especially critical for the elderly. Therefore, giving attention to programs that help to decrease the negative impact related with chronic illnesses associated with aging is important [21].

Self-Management of Chronic Conditions in the Elderly

Globally, the care of elderly persons with multimorbidity of chronic illnesses demands a shift in focus from episodic and acute care to a community-based approach prioritizing chronic management and prevention of diseases, emphasising self-care [9, 13, 17, 21]. In collaboration with healthcare givers, self-management training programs for elderly persons with chronic conditions have been typically offered in small groups in community settings such as churches, libraries, senior centers, and community health centers, especially in HICs. It is apparent that HICs such as Canada have a number of advantages when it comes to supporting and enabling elderly persons [23]. Canada has universal health coverage services for all its citizens. The Canadian Public Pensions System is widely commended for reducing poverty among older persons. Additionally, the Canadian Government supports initiatives aimed at improving access to information and resources. Elderly persons thus have access to financial support and needed information for self-management of their chronic conditions.

A scoping review focusing on elderly people with chronic conditions living at home in the United Kingdom gave some insight into their care and support needs [24]. Using the WHO International Classification of Functioning, Disability and Health (ICF) framework to analyze and categorize the findings, the review reported that this sample of elderly persons experienced physical, social, and psychological challenges. Interventions aimed at addressing these challenges therefore needed to focus on (a) social activities and relationships, (b) psychological health, and (c) activities related to mobility, self-care, and domestic life. The review also reported that many of the elderly demonstrated a willingness to manage their illness and maintain their independence, which is aligned with the WHO active aging framework [11, 24]. Unfortunately, the desired autonomy, independence, and quality of life are hindered by environmental factors such as (i) lack of professional advice on self-care strategies, (ii) poor communication and coordination of services, and (iii) lack of information on services such as care pathways. As self-management empowers individuals to manage these challenges, self-management model is key to healthy aging.

Having an understanding of the disease process and mastering the ability to conduct self-management tasks, such as making lifestyle changes and adhering to a medication regimen, could lead the elderly to successfully manage their chronic diseases [25, 26]. Positive psychological coping is required to deal with changes in health status and the accompanying limiting impact of the multimorbidity, which is strongly associated with higher mortality, poorer quality of life, and performance of daily activities and higher rates of health service use including emergency hospital admission [27, 28]. These result in loss of independence, increased need for institutional care, in-home caregivers, or other long-term services and support. The self-management model is shown to address physical and emotional factors that may trigger mental health issues to optimize quality of life despite the given circumstances [6, 28, 31, 32]. The programs have also resulted in health improvements in elderly persons with chronic conditions. These include improvements in blood glucose levels, decreasing blood pressure and pain, as well as maintaining levels of physical function. A decrease in healthcare usage and costs and improvement in health outcomes are also noted.

Senior Centers for Older Persons

There is preliminary evidence suggesting that the community-based self-management programs that address the challenges presented by chronic conditions are cost-effective [33]. Community-based senior centers can therefore be platforms where elderly persons can be empowered in the self-management of chronic conditions. The National Institute of Senior Centers in the USA described these centers as “community focal points on ageing where older adults come together for services and activities that reflect their experiences and skills, respond to their diverse needs and interests, enhance their dignity, support their independence and encourage involvement with the community" [32; p167]. According to subcultural theory, elderly persons adjust better to aging if they engage with individuals from a similar age group [34].The process of shared interaction results in a group consciousness with its own norms and values hence creating a subculture.

The senior centers provide the platforms for such subcultures and should be targeted [5]. It is assumed that the perceived benefits of socialization reported by elderly persons who utilize the services in the centers would provide the peer support and accountability in implementing the self-management program [35–37].

Strategies for Self-Management of Chronic Conditions on Senior Center Platforms

Acknowledging the determinants of active aging, self-management of chronic illnesses among elderly persons is conceptualized in community-based non-residential day centers for elderly persons (Table 8.3). While the six determinants of active aging can impact the implementation of self-management strategies, this chapter focuses on only two of the determinants, namely health and social care and behavioral determinants [11], which align with two of the common attributes of self-management, namely, continuous engagement with social supports and viewing health changes as being positive [9]. The WHO proposed that the health systems should focus on equitable access to quality primary healthcare and long-term care, health promotion, prevention of diseases, and mental health. An all-inclusive public health response to population aging that acknowledges "the wide diversity in the health, social, and economic circumstances of older persons, the disparities in the resources that are available to them, concurrent social trends, and changing

Table 8.3 Model for self-management of chronic conditions in senior centers – linking WHO goals, determinants of healthy aging, and benefits of senior centers

WHO framework on active aging [11]			Community-based rehabilitation (CBR) [20]	
WHO goals	Active aging determinants	Components of determinants	CBR matrix core components (and key elements)	Outcomes in senior centers (References)
Elderly person and development Advancing health and well-being into old age	Behavioral styles	Tobacco use; physical activity; healthy eating; oral health; alcohol; medications; adherence	Health (promotion, prevention)	[29–32, 35, 36, 37, 49]
Ensuring an enabling and supportive environment	Health and social services	Health promotion and disease prevention; curative and mental health services	Social (recreation, leisure, sports)	

aspirations" was proposed [23, 38; p. 660]. The care and support needs expressed by most elderly persons, despite their background health challenges, related to their desire to actively participate in the management of their chronic conditions to achieve their aspiration in maintaining their independence and shaping their own futures [24, 39–41]. Setting realistic goals for themselves could contribute to individuals being behaviorally engaged in life, motivating them to continue maintaining and/or aspiring to a behavior. Aligning with the three main goals of the active aging framework, elderly persons could therefore maintain control over their own personal development [11].

Transformation of the healthcare delivery system is needed to address the challenges of promoting the self-management ideal of shared decision-making with elderly persons [34, 42, 43]. While it has been widely recommended to engage patients with multimorbidity in shared decision-making, its application in routine clinical practice is not evident.

There is therefore a need to shift from disease-specific to patient-centered models of care. When implementing this approach based on patients' needs, healthcare providers are advised to obtain the preferences, concerns, and values of the patients and base the delivery of healthcare on these preferences. This will assist with increased patient involvement in healthcare decision-making, increased trust in healthcare professionals, and improved patient health outcomes. However, healthcare providers may struggle to help older persons define and prioritize their values, goals, and preferences in a manner that is clinically relevant and personally meaningful when there are numerous diagnostic and treatment alternatives to choose from. These difficulties, especially while interacting with elderly persons with multidimensional goals, could lead to the marginalization or under-acknowledgement of the non-medical goals of the client. It is proposed that the decision-making process should include, but not be limited to, the common concepts of the self-management model of chronic conditions [9].

Low health literacy is another major obstacle to self-management of chronic conditions [43]. It is more common in LICs, among people with fewer years of education and the elderly. Many elderly persons may not understand what their healthcare providers have said to them and therefore do not engage in decision-making, leaving them ill-prepared to make daily decisions and take actions that lead to good management [31]. The WHO encourages countries to assess and develop their own health literacy responsiveness, defined as "the way in which services, environments and products make health information and support available and accessible to people with different health literacy strengths and limitations" [43]. To enable patients to make good choices and sustain healthy behaviors requires collaborative relationships between health and other care providers, on the one hand, and patients and their families, on the other hand. This is to support the patients in building the skills and confidence they need to actively engage in decisions about their lives.

In addition, education programs for members and managers of the senior centers and families of the members are recommended. These training programs could be in the form of workshops for members of the centers or one-on-one consultations, depending on the preference of the affected elderly person. Given that chronic disease is the leading cause of morbidity, disability, and mortality of populations globally, the active aging framework emphasizes the need to address the risk factors [11]. Therefore, behaviors relating to tobacco use, physical activity, healthy eating, oral health, alcohol use, and use of and adherence to medications (prescribed or across the counter) should be addressed. Similarly, the factors that may impact the development of mental health issues should be addressed [8, 44].

The WHO recommends that the increasing burden of disease in the elderly would need community-based health promotion and disease prevention interventions [23, 45, 46]. In LICs and LMICs, physical inactivity is identified as a major contributor to the development of chronic conditions such as cardiovascular diseases, cancer, and diabetes [47]. Increasing physical activity and reducing the burden of chronic conditions should be the main goal of public health policies in these countries, and lessons can be learnt from HICs. Acknowledging the efficacy and cost-effectiveness of physical activity in the primary and secondary prevention of chronic diseases, Canada has invested resources in developing the Canadian Physical Activity Guidelines to promote healthy active living for all [48]. Similar physical activity guidelines exist for several HICs. One of the contributory factors to enhancing physical activity in the country was the conceptualization of physical activity that was not limited to sport and physical exercises [23]. It also includes activities individuals engage in when at work, home, in transport to and from places, or during leisure time [46, 49].

The rising trend in population aging is a “success story” [1, 2]. To prevent the reversal of the “success story” and make adequate preparation for future generations of elderly persons, it is necessary that countries, especially MICs and LICs, should strengthen their public health policies to prevent and/or delay the occurrence of chronic conditions that accompany normal aging. Encouraging physical activity, a cost-effective strategy, could delay the occurrence of chronic conditions. The WHO reports, however, that the percentage of people living with at least three of six health risk factors that contribute to chronic conditions (physical inactivity, current tobacco use, heavy alcohol consumption, a high-risk waist-hip ratio, hypertension, or obesity) rises with age. Therefore, supporting the elderly to self-manage is an important strategy to reduce the burden of chronic illnesses. In partnership with healthcare providers in nearby primary health care facilities, the senior centers become platforms where these support services are provided to assist elderly persons manage their chronic conditions.

Summary

The WHO determinants of active aging provide the framework for caring for elderly persons with or without chronic illnesses and the accompanying multimorbidity. The framework also provides guidelines to ensure healthy future generations of the elderly. Effective self-management of chronic conditions in elderly persons will improve the health of the aging population.

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Chapter 9

Community Health Workers as Key Contributors to Self-Management Programs

Jose Frantz, Levona J. Johnson, Zamantungwa N. Mvelase, and Janene E. Marais

Introduction

Community health workers (CHWs) who are hired primarily for their connection to a community have long been employed by primary care practices to provide a health service to the communities. The role of community health workers in community-based healthcare is essential and strategic, as they have a close link with the vulnerable people in the communities [1]. Community health workers are seen as agents of change by health authorities as they could facilitate community members to access healthcare [2], and the effectiveness of CHWs to deliver health care interventions has been demonstrated globally [3]. The literature related to African countries such as Ethiopia, Malawi, Kenya, and Mozambique highlighted that:

> specific interventions that strengthen support structures from the side of the community and introduce supportive supervision of CHWs from the side of the health sector need to be set up. These strategies should aim to enhance trust and thereby strengthen relationships between CHWs, communities and the health sector, which is needed to enable CHWs to respond to the opportunities offered by their unique intermediary position and promote universal health coverage [4; p1426].

Contextual factors, such as socio-cultural and gender norms and health policies, combined with intervention-related factors, such as training and supervision, can have a direct influence on motivation and performance [5]. There is a need to understand the context and conditions in which CHWs work better, in order to support them to improve their performance and realize their potential. In this chapter, we aim to highlight the context (psychological impact on CHWs rendering a service), conditions (consider the legal implications of CHWs as frontline workers), and performance (describe how CHWS are used to promote self-management of disease among community members) [4]. Linked to the importance of context, working

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conditions and performance as they relate to self-management interventions, we aim to highlight how practitioners can best utilize CHWs without compromising them in any way.

Psychological Impact on CHWs in Rendering a Service

The tasks of community health workers have evolved over the years, from focusing mainly on prevention and promotion to roles which are more supportive as a result of the rise of lifelong chronic conditions and non-communicable disease (NCD). Like many other countries in transition, South Africa has also experienced and been affected by lifelong chronic conditions associated with the increase in the HIV infection epidemic and parallel rise of NCDs [6]. This burden of disease has affected the healthcare system and those working at a primary healthcare level in major ways, as they have experienced an increase in their workload, overcrowding at health facilities, and poorer quality of care as a result [7]. Using CHWs is seen as forming part of the solution to the human resource crises experienced in the healthcare system [8]. Community health workers are used in many different contexts. They act as intermediaries between the communities in which they work (and are often a part of) and the health sector. They are essential in delivering preventative, promotive, and, on a smaller scale, curative health services, predominantly in low- and middle-income countries [4]. The global shortage of health workers has given rise to task shifting to lower-level health workers. Community health workers are one example of this and are often employed on a volunteer basis [9]. Community health workers have been playing a significant role in the improved health of many in rural and poor communities [3]. In countries such as Afghanistan, Bangladesh, Brazil, Ethiopia, and South Africa, the CHW program is an integral part of the basic health system of the country delivering health services to various communities who would otherwise have challenges receiving healthcare as part of self-management initiatives [10]. However, community health-based programs are riddled with problems, one of the most significant being attrition rates [11]. Adequate motivation can be considered an option to help with the challenge of attrition [12]. These motivators can be categorized into intrinsic (internal reward – empathy, altruism, pride, and a desire for self-fulfillment) and extrinsic (external reward – money, employment opportunities, material rewards, social status, and increased knowledge) rewards [12].

HIV/AIDS incidence and prevalence rates in Sub-Saharan Africa are the leading cause of disease burden [13]. This has escalated the need for palliative care community organizations that focus on vulnerable and orphaned children diagnosed with HIV/AIDS [14]. Community health workers are used to assist professional health workers as people living with HIV/AIDS and other illnesses need continued care, which cannot always be provided solely by professional healthcare workers. CHWs are essential to primary health care (PHC) outreach teams. They reduce the burden placed on the healthcare system, especially in low- to middle-income countries and communities [15]. Community healthcare workers often have no formal training and deliver care to communities, families, and individuals usually working through NGOs (non-governmental organizations), NPOs (non-profit organizations), and community-based organizations [16]. There are many factors which either improve or impede the effectiveness of the CHWs' ability to provide services and have an impact on their psychological well-being [17].

Reasons for Becoming Community Health Workers

There are various reasons why community health workers volunteer. Some of those reasons are for their personal development; personal recognition; wanting to help others; desire to learn and share knowledge; wanting to make a difference; religious beliefs, values, and morals; and being productive [11, 14]. Many CHWs decide to volunteer for their own personal development and to learn and share the knowledge that they gain. Personal development allows for the development of competence. Competence refers to one's belief in their capabilities to be able to skillfully perform tasks or activities [18]. Universally literature has indicated that CHWs value and desire to gain more knowledge, as these competencies are important drivers of the experience of feeling empowered for CHWs [18]. Being recognized and gaining respect from members of the community for their position as a CHW and rendering a service to the community served as important motivational factors for being a CHW [11]. Personal recognition can be a powerful motivational tool and incentive for improving work performance [19]. The religious beliefs, morals, and values of CHWs are driving forces why many CHWs volunteer. Religion plays a pivotal role in why many women volunteer. As a part of their religious duty, it is important that they give back and make meaningful contributions to their community [14]. According to the theory of social capital, the norms, the values and morals people have underlie and influence their behavior [20]. It thus becomes evident that intrinsic rewards are an influential motivator for CHWs to start or continue in their role as CHWs, even in the face of difficulties. Some of the challenges or difficulties with CHW programs are related to their integration into the health system or rather lack thereof. They face challenges with remuneration, training to carry out their tasks, classification of their scope of practice, referral systems, managing information, and limited supplies [21–23]. Due to the challenges that CHWs experience in addition to their limited skills, their work is often carried out in remote and isolated areas that gives rise to the importance of a supervision system that will assist in the monitoring of performance, but the provision of moral and other forms of support is also vitally important [24]. According to Kane et al. [19; p30] "for most CHWs, the work they do also carries a deeper meaning; for many it is an opportunity for self-actualization, for some a means to reify their faith and humanity, and for others a means to even define their identities."

Knowledge and Competencies Among CHWs and the Psychological Impact Thereof

The knowledge of CHWs is vital to the success of self-management care [13]. Community health workers are essential for the execution of health promotion which is proactive and the prevention of disease and self-management strategies. This is carried out by home visits to households in their designated area. For this model to be realized, the National Department of Health in South Africa has to face the challenges involved with training and educating of CHWs and outreach team leaders to work in ward-based outreach teams [25]. Community health workers have indicated that they feel that they do not have the necessary knowledge required for them to adequately perform their roles as key contributors to self-management care. The lack of knowledge for CHWs is a result of them not receiving adequate training to perform the tasks they have to perform [17]. The issues that they have identified include "knowledge in terms of palliative care itself, knowledge of psycho-social support, knowledge about antiretroviral and adherence treatment" [26; p336]. The lack of knowledge and training that CHWs receive impacts their sense of self-efficacy, emotional and mental competence, and self-esteem [26]. Self-efficacy refers to the "belief in one's capabilities to mobilize the motivation, cognitive resources, and courses of action needed to meet given situational demands" [27; p 408]. To improve CHWs' sense of self-efficacy, it is important that they have the knowledge and training needed to perform their tasks. A study conducted in Brazil suggested that a combination of educating the community on the role of CHWs working in the community and providing CHWs with the adequate training and resources will improve the communities' acceptance of CHWs and CHWs' ability to provide care [15].

Lack of Career Paths Has Negative Impact on CHWs

It has been found that CHWs are unaware of the term career pathing or what career pathing means. The missing link at some of these organizations is that they do not have a sufficient career development program in place. Career development programs (job resources) and training are important for the enhancement of job prospects [26]. Career pathing is a human resource development practice which aids in empowering employees to manage their careers. Additionally, it assists in the succession planning of the organization. Career pathing functions alongside practices of mentoring and development aimed at supporting learning and development. Previous research indicates that there are multiple beneficial work outcomes to career pathing, including retention and organizational commitment [28]. Career development programs are important for the fulfillment of the basic human needs of autonomy, relatedness, and competence [26]. Self-determination theory [29] posits that autonomy, competence, and relatedness are basic psychological needs that human beings have. If these needs are met then a person's enjoyment of activities will be promoted as well as their ability to regulate their behavior [30]. Intrinsic motivation is connected to basic psychological needs. If CHWs are intrinsically motivated on these needs, they are more likely to find enjoyment in their work, and job resources can aid in the fulfillment of these needs.

CHW Burnout and Exhaustion

There are three elements whereby work burnout can be identified: reduced efficacy, exhaustion, and cynicism [31]. Prolonged work stress can often lead to both health and mental health problems [32] and a decline in work productivity [33] and can cause an increase in staff turnover [34]. Health workers including CHWs can experience overwhelming emotional involvement, which is a form of emotional labor, increasing exposure to emotional exhaustion. Emotional exhaustion is a characteristic of emotional burnout [35]. Community health workers highlighted many reasons why they experience emotional burnout or exhaustion. These included a lack of proper supervision, work overload, no clear path for potential growth within the organization, no proper debriefing after encountering difficult situations in the field, a lack of stipend, and working in a dangerous environment [16]. Community health workers are also often exposed to many traumas in their personal lives, community, and work environment, which also has a psychological impact on their well-being.

For example, continuous trauma refers to the continuous nature of violence and trauma exposure in the South African context, even after the abolishment of apartheid. The most common form of traumatic exposure among CHWs is because they hear of traumatic events in work or personal life [36]. Exposure to traumatic events, whether direct or indirect, significantly impacted CHWs and their sense of safety, trust in others, and fear. The media also played a significant role in CHWs' exposure to trauma [36]. People are constantly bombarded with information in the media about what is happening in the country, and in different communities these include, but are not limited to, murder, gender-based violence, and motor vehicle accidents. Being constantly exposed to the violence portrayed in the media and in the community and in their personal lives constitutes continuous exposure to trauma and has an impact on the lives of CHWs [36].

Preparation Needed for CHW Self-Management Programs

Many CHWs cover the needs of an entire community, from children to seniors. Community health workers often feel they are not necessarily trained to provide psycho-social support to the children. The lay counselors also require training in counseling children because they are often better equipped to counsel adults but not children. Community health workers are also faced with the challenge of not having the knowledge to make antiretroviral treatment accessible to vulnerable and orphaned children. When they have to counsel orphans and vulnerable children, lay counselors have also revealed that it often left them traumatized, so that they themselves required counseling [26]. Community health workers require more and better training in preparation for self-management programs. Community health workers also require better supervisory support or counseling to help them cope with the hardships they face every day [16]. In addition, they require better support from the government and more equipment to be able to do their jobs [14]. Strategies need to be put in place to bridge the gap between health professionals and CHWs, as these relationships are often strained and CHWs often feel bullied by health professionals [17]. Remuneration is also important, as many CHWs don't have formal employment and they are poor. They may also lack funds for transportation to work [17].

Legal Considerations Allowing CHWs to Take Responsibility

A key issue of debate concerns the question of what functions individual CHWs can effectively perform, considering their level of education, and their type and duration of training, the health needs of the community, and the size and geographical spread of the population to be covered. CHWs can make a valuable contribution to community development and, more specifically, can improve access to and coverage of communities with basic health services. However, although they can implement effective interventions, they do not consistently provide services likely to have a substantial health impact, and the quality of services they provide is sometimes poor.

Scope of practice Very few countries have comprehensive policies regulating the practice of community health work [37]. When we consider the South African context, for example, community health work has been an initiative funded by the government through non-governmental organizations until 2011 in some provinces. There is no national or provincial policy regulating and protecting the work done by CHWs [24]. However, the South African government has issued minimum requirements and guidelines as to their functions for those who wish to become CHWs [38].The work done by CHWs is of great significance to the communities they serve, especially those who attend to the poor, and in remote/isolated areas as they are usually the first point of call for healthcare purposes [39]. Their work promotes inclusion of possibly marginalized people/groups in the healthcare system. Thus, they play an integral part in the realization of the universal right to healthcare [40]. The practice of community health work can be traced back to the seventeenth century in Russia, where it came about as a response to a great shortage of medical staff and it later became a common practice all over the world [41]. However, the scope of practice for CHWs varies in different countries. It is important to note that their scope of practice is generally limited when it comes to tiers pertaining to healthcare [42]. This affects the extent to which they can assist their fellow community members and ultimately it negatively affects the attempts of an inclusive healthcare system. With global issues, such as an increase in migration, natural disasters, and declining economies on the rise, most healthcare systems around the world are overwhelmed and in extreme instances inaccessible to those who need them [43].

The Right to Health Under International Law

The right to health was first articulated in the preamble of the 1946 constitution of the World Health Organization [44]. It was first protected under international law in the Universal Declaration of Human Rights (Universal Declaration), specifically in Article 25 (1) which provides for it that:

> Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. [45; p4].

The meaning and scope of the right were further elaborated on in the International Covenant on Economic, Social and Cultural Rights under Article 12. Article 12(1) of the abovementioned convention provides for it that all state parties to the convention must recognize everyone's right to enjoy "the highest attainable standard of physical and mental health" [46]. The right to health currently enjoys extensive protection under international law as it is mentioned in various treaties and therefore justiciable in various countries as a consequence of international law [47]. Self-care management, especially in cases of chronic illness, has proved to be a useful tool. It empowers patients to be in charge of their own health. However, people need knowledge and support for it to be effective [48]. This is where CHWs assist communities, especially in cases where access to healthcare is limited. CHWs often go above and beyond their call of duty. Reports indicate that some CHWs go as far as cooking and buying food for patients who are too ill to tend to those needs themselves. Some CHWs use their own resources to ensure that some patients get to primary healthcare facilities [24]. They fill in the gaps where primary healthcare falls short, reaching communities in ways that gives dignity to the patients they interact with, promoting equality within the healthcare system and overall quality of life [37]. The universal right to healthcare can only be achieved by informing people of their legal right to health care, equipping them with ways in which they can access care and understanding how to participate in their own health care [49]. CHWs are agents who have the potential to champion this to a great extent in their various communities, but in most states, they are not recognized as an official/formal part of the healthcare system. Despite positive evidence supporting that CHWs have the potential to improve patient health outcomes and reduce health care costs, they are still not regarded as a formal part of the healthcare system in many countries. This affects CHWs negatively when it comes to issues of job security, budget allocations, support, and supervision, and this ultimately impoverishes the communities/persons they serve. Very little to no legislative measures exist that recognize CHWs as an official part of the healthcare system [50]. Formal integration of CHWs into the healthcare system would be a great benefit, as they can be regarded as a true extension of the healthcare system in their respective communities. This will be beneficial in building trust between community members and CHWs, especially when dealing with confidential matters, as CHWs would be subjected to the strict client confidentiality standards of the formal healthcare system [51].

CHWs are bridging the gap between the healthcare system and everyday community needs. They are often first responders to community members with respect to healthcare matters. Therefore, there is a need for them to be equipped with the necessary training and guidance to allow them to respond effectively when the need arises. There is a clear and direct need for efficient policies and legislative frameworks that will attend to the regulation of CHWs, which will in turn create certainty and enable them to do so much more for their communities.

Community Health Workers Promote Better Health with Self-Management Interventions

Although we have reported on the psychological impact and the legal implications for community health workers, and acknowledge the evidence of these barriers, their role in promoting health is still valuable. Community health workers were identified as good partners to help health professionals improve the self-management skills of patients [52]. Perry *et al.* [53] emphasized that this can only be effective if the role of the CHW is well understood by the health professionals and if the health professionals can effectively use the CHWs as part of healthcare teams. This could possibly also address burnout among CHWs. Unlocking the potential that CHWs contribute to healthcare and using it to enhance overall healthcare have been promulgated in the WHO guideline on health policy and it aims to fast-track the global goal of "Health for All" [53]. This idea that CHWs can play an effective supporting role is supported in the literature highlighting that CHWs play an active role in driving structured education, providing support, and promoting health system advocacy for self-management interventions for patients [54]. They also advise that in order to get effective service from CHWs, they should be provided with training, as this would enhance the quality of support they provided. It has also been noted that the skill sets of CHWs can be improved if they receive support from a designated supervisor [55]. CHWs can be also used to screen the mental health conditions of patients which are social determinants of health and food insecurity [56]. They can then be used to assist the patient by providing and linking the patient to community resources and referrals to relevant health professionals.

CHWs are competent enough to not only refer the communities to the relevant health services, but they also are capable of effectively educating community members about health risks and disease [57]. Studies show that CHWs have made a significant contribution to improving adherence to antiretrovirals in the management of HIV in Sub-Saharan Africa [58]. Further studies have reported that CHW-led interventions resulted in the improvement in the self-efficacy and quality of life in HIV patients [59] and that it has made significant strides toward achieving the 4th and 5th Millennium Development Goals (MDGs) to reduce child mortality and improve maternal health, respectively [53]. This group of the healthcare team has also yielded good results in medication adherence and self-management in hypertensive sufferers [57]. Recent studies have confirmed that these interventions yielded good disease control not only in hypertensive patients but also in diabetic patients [60]. In low- to middle-income countries (LMICs) such as South Africa, ensuring that communities receive quality primary healthcare is important. In a study conducted in the Limpopo Province, South Africa, researchers concluded that marginalized communities benefited greatly from the capable and effective health services rendered by CHWs in rural areas. They placed the emphasis on the rolling out of self-management principles, citing that it will simultaneously improve CHWs' connection with the communities and enhance the trust that communities have in them [61].

It is imperative that in future the medical practitioners learn how to effectively integrate CHWs as part of a genuine all-encompassing multidisciplinary medical team [62], especially as the expectation for them is to equip the communities to improve their own health risk behaviors. Health professionals treating medical conditions in Japanese elderly found a gap in the multidisciplinary team approach [63]. They reported that the dissatisfactory interaction and poor understanding that exist within medicine-specific disciplines (including CHWs) should be urgently remedied and suggested that the medical approach adopted by cancer centers globally be used as a yardstick. A qualitative study conducted in South Africa focussing on national guidance and practices to supervise CHWs reported that the relationship between facility-based medical staff and CHWs is generally referred to as "strained," and that although CHWs are deemed crucial, there seems to be a poor understanding of how to sustain the supervision this group requires [64]. In the National Department of Health (2018), the challenges experienced by CHWs are clearly outlined and include the uncertainty of being considered neither a volunteer nor an employee of the department of health, poor remuneration, expectation to be multitaskers, lack of supervision, lack of acknowledgment, lack of respect, and being undervalued [65]. Despite CHWs perceiving themselves as adding great benefit to the communities and even considering themselves fulfilling medical support roles such as social work [66], the concern that these challenges will lead to demotivation is acknowledged [64], and if not addressed, it will lead to a weakened CHW workforce making sustainable community-based healthcare difficult [67]. This will inevitably derail the aim to decrease the quadruple burden of disease that South Africa is currently facing.

Self-management support can take place in several ways, such as one-to-one communication between the patient and healthcare professional, family member, or peer; in disease-specific group education programs; in group settings led by either peer leaders or health providers; and through interactive technology, e.g., via social media platform, WhatsApp which transcends economic divides, and/or internet if access is possible for all stakeholders. In recent years, the main task of managing one's chronic health condition has been shifting to the patient. Yet a considerable responsibility still remains with healthcare professionals who can use their expertise to inform, activate, and assist patients in the self-management of their conditions.

While we acknowledge that the term "self-management" is not a new one and that every individual has to perform a certain level of daily management of themselves [68], it is true that not all patients are keen to be active participants in their own healthcare. The term "self-management" mostly referred to interventions, activities, and health promotion programs, but it is packaged with specific skill sets, such as decision-making, goal setting, taking action, and forming partnerships with healthcare providers [69]. These essential skills are imparted to the communities to varying degrees as CHWs go about their roles of promoting better health practices in the communities with the wide range of promotive, preventative, and curative health services supporting patients suffering from chronic diseases, reaching out to improve the communities' access to healthcare and reducing inequities, being advocates for the communities, and offering coverage of primary healthcare services [70]. There is a reliance on the social persuasion effect to be the catalyst in these self-management interventions in order for the broader community to be reached. The impact of these interventions takes the society at large one step closer to achieve the global movement goal of "Health for All."

Interventions That Can Be Used in Communities by CHWs

Some of the most important considerations health professionals need to bear in mind when engaging community health workers as a group/team to drive self-management initiatives are highlighted by Sandler, Wolfe, and McKevitt [71]: (i) self- management approaches should have an empowering approach rather than a paternalistic approach; (ii) self-management approaches should incorporate a psychosocial model rather than only a psychological approach; and (iii) the interventions should be focused at the level of the competency of the lay person [8]. Advocacy for health, support, and structured health education talks were the common ingredients of effective self-management among CHWs [54]. The CHW roles themselves have been outlined into six themes which include capacity building, acting as an advisor, monitoring the clients, providing health services, connecting the community to the health system, and administrative duties [8, 54], all of which are amenable to self-management approaches.

Self-Management Approaches Should Empower Individuals

In order to ensure that self-management approaches empower participants, managing behavioral change can be achieved by being equipped to self-monitor and track themselves [72]. "Empowerment" can be defined by stating that it is "the process by which relatively powerless people work together to gain control over the events that determine their lives and health" [78; p1]. It is important that individuals are spurred on to seek empowerment in their own health management [73], because as the individual is reached with improved health, the snowballing effect will become evident in the communities and the continuum for health empowerment will be established [74]. The result is an increased sense of self-determination and self-efficacy [75] which will positively affect the global burden of disease. To date there is an extensive amount of evidence indicating that CHW-led interventions in diabetic sufferers have shown improvements in disease knowledge and medication adherence [60]. Knowledge is power and thus as we increase knowledge, we are contributing to the empowerment of the community.

Self-Management Approaches Should Incorporate a Psychosocial Model Rather than Only a Biomedical or Psychological Approach

Healthcare has shifted from the biomedical model to the biopsychosocial model, which highlights that biological, psychological, and social factors determine health. Adverse psychosocial factors are associated with health risk behaviors and a poor quality of life [76]. Psychosocial barriers in diabetic self-management interventions have been defined as psychological and interpersonal factors that impede diabetes management or a diabetes-related quality of life [77]. Psychosocial barriers which emerged in diabetes self-management are poor family support and self-efficacy, followed by depression and the fear of hypoglycemia. With this in mind, behavioral interventions in diabetes are now focused on empowering the patient and providing them with motivational support to facilitate them to investigate the best manner to handle their condition [78].

Social support, which is regarded as the positive feature of social relationships, enhances the individual's sense of control, improves self-related physical health, and is associated with a decrease in physical disabilities [79]. This is an important aspect to consider when presenting self-management interventions to the public, and the education using this strategy should target all categories of age to allow healthy behavior patterns to be developed early and thereby minimize the profound negative consequences of unwholesome health behaviors over a lifespan [76, 79].

The Interventions Should Be Focused at the Level of Competency of the Lay Person

Self-management has its roots in educating lay people to manage their chronic conditions [80], and therefore by its very nature, it is geared to utilize educational material at the competency level of the trainees. The interventions should maintain the needs of the individual as a central part of the engagement and then utilize the process of empowerment to upskill and give impetus to capacity building [81]. Recently, the requisition for trainers/presenters of health interventions to be "culturally competent" has increased [82]. "Cultural competence" has been defined as a "set of skills, attitudes and practices that enable the healthcare professionals to deliver high-quality interventions to patients from diverse cultural backgrounds" [83]. While the term "cultural competence" is somewhat controversial amid growing recognition of the complexity of culture, cultural awareness and cultural humility are critical for effective healthcare of diverse populations. Having the skills without the behavioral capacity/competence is not sufficient when imparting knowledge, especially in healthcare in which the healthcare worker is expected to personify the health system's practices. The most important two competencies reported are (i) the practice of community health, wherein the CHW is the champion for the needs of the community, and (ii) diversity and inclusivity, whereby the CHWs interact with the different individuals in their communities in an unbiased manner [84]. This nucleus of workers has the advantage of sharing socioeconomic, cultural, racial, and ethnic factors with the communities they serve and sometimes even live in and share the medical conditions present in their communities [85]. CHW self-management training needs to ensure that education is led by lay persons trained to their level of competency. As community leaders execute this approach in a less formal way, using appropriate language and employing alternate ways to expound on health advice, they will not only be modeling healthy behaviors and be improving self-efficacy, but they will also be promoting the community trainees to become active participants in managing their health holistically [86].

When the trainees of community members are equipped to do self-care, are supported, receive regular feedback about their action planning, receive encouragement, have counseling to boost their effectiveness, and are aided to develop and improve their current coping mechanisms, there is a significant impact on health outcomes [87].

Conclusion

An intervention should empower CHWs to gain knowledge on self-management and convey that knowledge in a culturally appropriate fashion that should positively impact the communities they serve. CHWs are ideally positioned in the healthcare sphere to make a difference and contribute to meeting the healthcare agenda of any country. Self-management training can enhance the skills of community healthcare workers and all healthcare professionals to perform their duties more effectively. Once they themselves are empowered, the health promotion and health education they execute will more effectively address the WHO recommendation that states:

> …health promotion should include empowerment strategies such as promoting community action through collective involvement in decision-making and participation in all phases of public health planning, implementation & evaluation, use of lay helpers and leaders, advocacy & leadership training & organisational capacity development [88; p5].

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Chapter 10
Self-Management in the Workplace

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Introduction

According to the World Health Organization, 71% of all deaths worldwide are due to non-communicable diseases, the top four of which (cardiovascular disease, cancer, respiratory diseases, and diabetes) account for 80% of all premature non-communicable disease deaths [1]. Investing in better management of these chronic diseases is critical. Disease management includes screening, treating, and providing ongoing care to individuals in need [1].

The United Nations underscored the rights of persons with chronic health conditions to participate fully in work and community life through the Convention on the Rights of Persons with Disabilities, and all countries face growing needs to support the health of employees. For example, a majority of the US adult population has one or more chronic conditions that require treatment and long-term self-management [2]. There are an estimated 206 M working-aged adults between 16 and 64 years [3]; however, workers age 60 years and older represent approximately 19% of the nation's employees [4]. As the workforce ages, the prevalence of chronic conditions continues to increase, with at least half of adult workers reporting one chronic condition and one-quarter with multiple chronic conditions [5]. Given that 90% of annual US healthcare expenditures are for individuals with chronic conditions including mental health issues [6] and the average annual premium for employer-sponsored health coverage was over $20,000 USD [7], workplaces should actively promote interventions to prevent and manage chronic conditions.

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Since chronic disease management efforts may have the largest impact on employers' healthcare costs, and in light of an 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 rationale for self-management in the workplace. It explains the unique context of the workplace, how it is different from community and clinical settings, and how self-management should be incorporated into workplace programs. This chapter highlights legal and ethical issues, presents case descriptions of self-management programs conducted in workplaces, and concludes by offering future directions for self-management programs in the workplace.

Workplace Context

Workplaces have been identified as effective settings to reach individuals with health-related messages or programs for a number of reasons. A large percentage of the population is employed and spends a significant amount of their time at work. Workplaces have established communication systems, means for monitoring employee activities, natural support systems, and incentive and reward systems. Furthermore, workplaces in countries such as the USA often provide access to the healthcare system through employer-sponsored health insurance programs. Worksites also have at least some control over their physical environments, which can be modified to support healthy behaviors.

While there are numerous advantages to offering health-related programs in worksite settings, there are also challenges to implementing such programs [8, 9]. Even the best worksite health promotion programs in the most dedicated organizations frequently are of low priority and suffer from insufficient infrastructure and resources. Workers are hired to perform certain tasks or responsibilities for an organization, and activities that distract workers from those tasks are generally perceived negatively. Outside of corporate headquarters, most company sites do not have trained health promotion staff, adequate facilities, and/or strong enough management support to conduct the programs effectively. This is particularly true of small-to medium-sized organizations [10]. As a result, any intervention designed for worksite settings must be relatively easy to implement, cost-effective, and minimally disruptive of normal work operations [8].

Impact of Chronic Conditions at Work

Over the last five decades, the workplace has become an important avenue for reaching a large portion of the population with programs and activities to improve their health. Although early efforts were primarily focused on disease prevention, employers quickly understood the significant impact of chronic diseases on the health and productivity of their employees [11]. Chronic health conditions are the primary reason employees leave work prematurely [12, 13]. In a random sample of 7800 Dow Chemical Company employees, two-thirds reported having one or more chronic conditions [14]. Data from a large healthcare organization showed 75% of employees had one or more chronic conditions, 54% had two or more conditions, and 16.5% had five or more conditions [15]. Since the majority of adults in the USA are employed, the most prevalent chronic conditions among US workers mirror those in the general population: cardiovascular disease, cancer, stroke, COPD, and diabetes [16].

Employees with chronic diseases often have difficulty meeting work demands. For instance, Lerner et al. [17] reported that, depending on the chronic condition involved, between 22% and 49% of employees experience difficulties meeting physical work demands, while between 27% and 58% have problems meeting psychosocial work requirements. In a study of approximately 1700 workers across multiple organizations who participated in a health screening, 55% reported physical or cognitive difficulty or both in performing work tasks, and the average number of chronic conditions reported was 3.5 [18].

The workforce in many countries is aging. The global population over 60 has doubled since 1980, and projections indicate that by 2050, there will be more older individuals (60 years or older) than adolescents and children (24 years and younger) [19]. A number of governments are seeking to increase statutory retirement ages and eliminate age barriers in the labor market to promote the recruitment and retention of older workers [19]. In the last 20 years, employment of workers 65 years and older in the USA has grown by 117%, employment for older women has grown faster than for men, and employment for those 75 and older has grown likewise by 117% (Fig. 10.1) [20]. Most of these older workers will have one or more chronic diseases; 81% of US adults 65 years and older have two or more comorbidities [21].

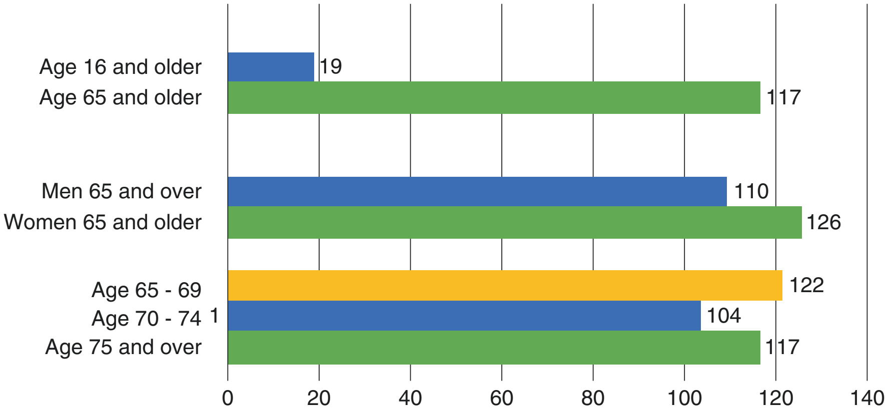

Fig. 10.1 Percent increase in employment by age and sex 1994–2014. (Source: National Institute for Occupational Safety and Health, Centers for Disease Control (https://www.cdc.gov/niosh/topics/productiveaging/dataandstatistics.html))

This has led some researchers to conclude: “Employers, and society more generally, must address the implications of the aging workforce and the rise in the number of chronic conditions in the overall population for workforce productivity and gainful employment, including for aging workers” [18].

Cost of Chronic Conditions at Work

Work organizations are impacted by employee absenteeism, healthcare costs, and lost productivity. Jinnett [18] has reported increased absenteeism and decreased productivity among employees with chronic conditions compared to those with no chronic conditions. Collins [14] showed the average annual cost for each employee with a chronic condition was $2278 for medical care, $661 for absenteeism, and $6721 for lost productivity. Across the entire company’s workforce, that accounted for 10% of the total labor costs (in 2002 US dollars).

In a study of 33,324 employees of a large healthcare organization, the number of chronic conditions increased with age and the annual healthcare cost increased with the number of chronic conditions [15]. Forty percent of employees 18- to 34-year old had no chronic conditions, whereas only 9% of employees 50- to 64-year old had no conditions. At the upper end, the number of employees with five or more chronic conditions was 5% for 18- to 34-year-olds and 33% for 50- to 64-yearolds. Overall, the average annual cost for an employee with no chronic conditions was $2137, while the cost for an employee with five or more conditions increased tenfold to $21,182. As a result, helping employees manage their chronic conditions has become an important component of workplace health promotion efforts.

Getting individuals to take an active role in managing their health has been recognized as a crucial strategy for addressing chronic disease [22–24] and has led to the integration of disease self-management practices in the workplace and other clinical and community settings. Adults with chronic diseases are constantly required to make decisions that affect their health and functional capacity, which also have ramifications for work performance and employability. Work organizations are acutely aware of this and increasingly looking for ways to support the health and well-being of their employees, particularly those with chronic conditions.

Importance of Self-management at Work

Work and workplaces are especially significant for individuals with chronic conditions and can be essential to effectively managing those conditions. Treatment and management of chronic conditions can be expensive, depending on the condition or conditions. Work provides a source of income that can pay for the cost of treatment and ongoing costs associated with management of the condition. Workplaces that offer insurance to their employees can significantly reduce the overall cost to that employee.

Work can be physically or mentally demanding, depending on the type of job. These demands may impact on the management of the chronic condition by requiring individuals to adjust what they do during that period of time (while at work) and/or what they do before or after that time (while at home). For example, if the individual must take medication or perform other tasks (i.e., monitor blood sugar) at certain times, their ability to do so may be affected by their work. As such, for working-aged adults, the most relevant interventions are those that focus on the employees' conditions and healthful behaviors to self-manage such conditions, with an emphasis on work-life balance and the reciprocal influences of time spent at work and at home.

Some jobs require employees to travel to distant locations or work offsite. These periods of travel can impact on employees' ability to manage their condition by distancing them from their healthcare provider and/or requiring them to modify their daily activities (e.g., sleeping, eating, and physical activity). It is in the interest of both the employee and employer to support the management of chronic disease, which can enable employees to efficiently and effectively maintain or improve their health and well-being, control their medical costs, and be retained within in the workforce until they elect to depart.

Current Workplace Disease Management Programs

Chronic disease detection and management programs have been a cornerstone of worksite health promotion efforts for decades [25]. Most of these efforts have mirrored national public health initiatives to reduce rates of cardiovascular disease, cancer, and diabetes. However, initiatives have also included programs of particular relevance to worksites including back pain, depression, asthma, and obesity.

Worldwide, workplace health promotion programs vary greatly and are influenced by social and community norms, sources of funding for health care, local and national laws, and the presence of organized labor. In a national study of US worksites, 46.1% offered some form of health promotion program, with a substantially larger proportion of large companies with 250+ employees (i.e., 83% to 91.8%) offering programs [26]. The most prevalent topics covered in these programs included physical activity (28.5%), nutrition/healthy eating (23.1%), stress management (19.6%), tobacco cessation (18.5%), and obesity/weight management (17.4%). The most common disease management programs offered were for hypertension (19.7%), diabetes (19.5%), high cholesterol (18.9%), and obesity (18.6%) (Table 10.1) [26]. Availability of the programs varies greatly with the size of the worksite. Although the majority of large worksites offer a variety of disease management programs, smaller worksites have traditionally lagged behind larger worksites in their ability to provide programs to their employees.

Table 10.1 Prevalence of disease management programs by size of worksite (number of employees)

Program	Total	10–24	25–49	50–99	100–249	250–499	500+
Hypertension	19.7%	16.9%	18.3%	18.4%	40.0%	52.6%	75.4%
Diabetes	19.5	16.8	18.3	18.2	37.4	55.4	75.9
High cholesterol	18.9	16.3	17.4	17.7	38.9	44.8	71.7
Obesity	18.6	16.0	17.6	16.1	38.5	44.5	74.4
Cancer	16.6	15.2	14.0	14.7	32.5	41.9	62.6
Depression	15.1	11.3	16.2	15.1	35.4	43.2	67.4
Asthma	11.2	8.3	13.0	10.3	24.7	27.0	57.8
Migraine/headache	8.9	7.9	8.9	4.9	20.3	21.6	38.5

Source: CDC [26]

Of sites offering a health promotion intervention, between 87% and 98% were informational in nature or a combination of informational and skill-building in nature [26]. In a literature review of workplace interventions in the USA, it was found that most targeted specific chronic conditions (e.g., cardiovascular disease, diabetes, and obesity) and were hosted on-site [27]. Eighty percent included educational and informational strategies, 60% included health coaching or one-on-one consultation, 36% included internet-delivered components, and 24% included environmental change components. Of the workplace interventions examined, 60% were multi-component interventions [27]. Although not reported specifically by program, a majority of worksites reported the program was an in-house program, managed by their own employees (62.3%), compared to programs managed by vendors (21.5%) or programs managed by health insurance providers (16.2%) [28].

Despite the growing need, few worksites provide disease management programs and even fewer are evidence-based. There is an opportunity to provide more services but there are a number of barriers that must be overcome. For small organizations, they may need to partner with community resources to offer services [10]. In the very small businesses, there may only be a few employees with a condition creating barriers related to privacy and confidentiality, protection of health information, and stigmatization. However, even in small organizations, the question has shifted from “why should we offer programs?” to “how do we offer programs?” [29].

Worksite Self-Management Programs

Most disease management efforts in worksites primarily consist of screening for early detection and referral to the employee’s healthcare provider for appropriate treatment. The typical workplace does not play an active role in helping the employee self-manage their condition once identified, other than to make work accommodations according to company policy or federal guidelines (e.g., Americans with Disabilities Act). This reflects early self-management initiatives nationwide which were largely centered in clinical domains with little consideration of social environments or communities [22] and were primarily focused on disease information and medication adherence [2]. Worksites should embrace self-management programs as part of their overall efforts to support employee health and well-being, and there are some promising examples of programs that have been effective within worksites.

Case Descriptions of Self-Management Interventions in the Workplace Context

In this section, two case descriptions are provided to illustrate examples of disease self-management programming in workplace settings. Both examples incorporate the Chronic Disease Self-Management Program (CDSMP), the most widely implemented and evaluated disease self-management program in the USA and worldwide [30–32].

CDSMP was originally designed to help adults develop self-management skills to cope with and manage the symptoms resulting from their chronic conditions [33]. Based primarily on the Social Learning Theory [34], this 6-week program is led by two trained leaders who are considered to be peers of the participants. One 2.5-hour session is hosted once a week for six consecutive weeks. During the workshops, participants cover topics including (but not limited to) physical activity, sleep, nutrition, communication with others, evaluation of medical treatments, and management of negative thoughts and emotions [35]. While the program content is generally appropriate for persons with any chronic condition, it is a process-driven intervention that facilitates the development of symptom management skills and adaptive coping strategies by utilizing well-tested behavior change strategies such as action planning and feedback, behavior modeling, problem-solving techniques, and decision-making [36].

CDSMP has proven effective for improving health status and reducing healthcare costs in populations with diverse chronic diseases [37–39]. Originally developed for the populations of ages 50 years and older, CDSMP has traditionally been delivered through the aging services network in multiple community settings including senior centers, healthcare organizations, residential facilities, faith-based organizations, and recreational facilities [40, 41]. However, despite the longstanding and robust delivery of CDSMP, the structure and format of CDSMP were not suitable for widespread adoption in work settings. To date, only between 0.05% and 1% of CDSMP participants were reached in workplace settings [30, 41].

Case Description #1 Live Healthy, Work Healthy (currently wCDSMP). In this study, researchers initiated a coordinated effort to identify and overcome worksite implementation barriers, translate CDSMP for use in workplace settings, and improve work performance indicators while maintaining the program's well-documented health-related effectiveness [9]. The translation involved an extensive process that included working with the original program developer, gathering input from CDSMP Master Trainers and seeking guidance from employees with chronic diseases. The translated wCDSMP was modified and tailored for working-aged adults in terms of format and content [42]. Changes in format primarily involved making the program more worksite-friendly by delivering two 50-minute sessions a week over 8 weeks, rather than six 2.5-hour sessions over six weeks. Modifications to the content were designed to address work-related topics and provide work-relevant examples. The program emphasizes work-life balance, stress management, and communication with supervisors and coworkers. Additionally, information about falls at home was omitted and information on nutrition and physical activity was adapted to apply to the general population.

In a randomized-controlled trial (RCT) conducted in worksites, the researchers tested wCDSMP compared to the standard CDSMP, measuring participants' self-reported health behaviors, self-management measures, and biometric data. Data were collected at the beginning of the trial, at 6-month follow-up, and 12-month follow-up. When examining baseline to 6-month findings, many self-management behaviors were observed among participants of both intervention arms; however, more benefits were observed among those who participated in wCDSMP. Compared to CDSMP participants, wCDSMP participants reported significantly larger improvements in fatigue, physical activity, soda/sugar beverage consumption, and work limitations from mental demands ($P < 0.5$) [42]. Many of these findings confirm findings from other studies among working-aged adults participating in CDSMP [43].

Based on the efforts of this RCT, wCDSMP has been recognized as an evidence-based program by the Administration for Community Living [44]. Having been vetted by an independent Review Council, meeting this highest-tier evidence makes wCDSMP eligible for Older Americans Act Title III-D funding and inclusion in ACL grant proposals [45]. As of March 1, 2020, approximately 255 CDSMP Master Trainers had been cross-trained in wCDSMP. These Master Trainers come from 38 states. Additionally, organizations in ten other countries (Australia, Barbados, Canada, Chile, China, Finland, the Netherlands, New Zealand, Taiwan, and the United Kingdom) have been trained and are offering wCDSMP to employees [35].

Case Description #2 SMART Life Study. In this RCT, researchers tested the effects of the non-translated CDSMP among lower- to middle-age working adults between the ages of 40 and 64 years (46). The CDSMP was compared to an attenuated attention control financial self-management program on employees with 1+ chronic conditions working 32+ hours per week. All workshops were hosted off-site and mostly off work time. Self-reported survey data were collected at the beginning of the trial, at 6-month follow-up, and 12-month follow-up. While attrition was identified as an issue, participation was highest among racial and ethnic minority participants [46]. Furthermore, participants reporting depressive symptomology and those with higher body mass indexes reported a significantly higher preference for attending CDSMP compared to the financial self-management program [47]. Findings suggest the potential of CDSMP to attract lower-wage and racially/ethnically diverse participants. However, issues with recruitment and workshop attendance support the need for translated efforts to introduce and embed CDSMP on-site, on work time [42].

Ethical and Legal Issues for Workplace Programs

Chronic disease management initiatives are increasingly included within workplace health promotion programs. This is not surprising given the prevalence of chronic conditions in the workforce, the aging workforces in most developed societies, and the potential health and financial benefits associated with effective disease management. However, almost from the very beginning workplace health promotion, efforts have raised a number of ethical concerns [48–51]. A quick review of the more recent literature suggests that these concerns have not disappeared [52–55]. Four interconnected ethical issues have endured in these discussions: privacy/confidentiality, coercion (voluntariness), victim-blaming/stigmatization, and conflicting loyalties.

Privacy and Confidentiality

At the core of this issue is the extent to which employers have the right to interfere with the lifestyles and health-related behaviors of their employers. For example, in the USA, many employers provide health insurance benefits for all or most of their employees. Does this financial stake give them the right to collect and use personal health information on employees? Workplace health promotion programs (WHPP) frequently utilize health risk appraisals, biometric screenings, and other data collection tools to determine employees risk levels, recommend programs and interventions to specific employees, and assess programs' outcomes and costs. To what extent might personal health data be used for other purposes, such as employee retention or promotion? Employees in the USA enjoy some legal protection, including the Americans with Disability Act (ADA), the Health Insurance and Portability and Accountability Act (HIPAA), the Pregnancy Discrimination Act (PDA), and the Genetic Information and Nondiscrimination Act (GINA). Each of these laws is intended to minimize discrimination based on health or disability. Protecting worker privacy is an important component of this protection. However, these laws are each complex and contain multiple provisions. With this complexity, there are often various gaps, oversights, and inconsistencies. Under the ADA, for example, there is a "safe harbor" provision for workplace health promotion programs conducted in conjunction with a benefits plan whether offered by an employer, insurer, or other entity [53]. Such programs are exempted from certain ADA restrictions on unnecessary medical examinations and inquiries contained in the workplace clause of ADA.

Coercion (Voluntariness)

Virtually from the beginning, workplace health promotion initiatives have been largely voluntary, that is, employees could choose to participate or not. But early on, questions were raised about whether WHPPs are ever "really" voluntary or whether there are subtle or sometimes not-so-subtle pressures to participate in program activities [51]. The issue of coercion is in the spotlight today as more and more employers and insurance providers employ various types of incentives or penalties to boost participation in WHPPs. In 2007, 66% of insurers indicated that they were somewhat or very likely to employ incentives for health-enhancing behaviors and 44% said they would probably charge higher premiums for members with characteristics that put them at higher risk [56]. Results from a recent large-scale survey showed that 29% of small firms (3 to 199 workers) and 62% of large firms (200 or more workers) in the USA used incentives or penalties to encourage employees to complete personal health risk assessments [57]. Receiving an incentive for completing a health-risk appraisal would be an example of a participation incentive; being rewarded for maintaining a certain body-mass index would qualify as an outcome incentive. Some US legislation designed to protect healthcare consumers actually makes it easier for insurers and employers to use financial incentives/penalties under certain circumstances. For example, under the Health Insurance Portability and Accountability Act (HIPAA), it is relatively easy for employers and insurers to use participation-contingent incentives but more difficult to use outcome-contingent incentives [56].

Victim-blaming and Stigmatization

The central issue here is the extent to which the individual is in some way responsible for his or her health condition. Once blame is assigned, the potential for stigmatization is obvious. Victim-blaming and stigmatization have been longstanding issues in health promotion and public health more generally [58]. For example, to what extent is an obese person with type II diabetes responsible for their condition? DeJoy and colleagues [52] posed the following question: "Is an employer engaging in victim-blaming when less healthy employees are required to pay more for their health insurance than healthier employees, or when they fail to hire an otherwise qualified job applicant who is obese (p. 361)?" The tendency of workplace health promotion programs to focus on individual behaviors and risk keeps the issue of victim-blaming relevant. With respect to chronic disease management, particularly, self-management, this risk remains prominent. Is it valid to assume that all people are genetically equal, fully rational, equally informed, and equally in control of their lives and circumstances [59]? Are all employees competent to manage their conditions, especially under stressful or otherwise demanding circumstances? Is self-management the best choice for all individuals? [60, 61].

Conflicting Loyalties

Those charged with managing and conducting workplace health promotion programs are typically company employees or contractors. What is their responsibility to program participants versus the company or organization that employs them? These dilemmas or conflicts were noted early in the health promotion movement, particularly in the context of WHPPs [50, 51, 62]. For example, in the attempt to boost program participation rates, might practitioners recommend activities that might not be in an individual worker's best interest? After all, employers may very well look at participation rates and program outcomes in evaluating the job performance of their health promotion specialists. As more employers invest more in WHPPs, they will naturally expect more from them, making these issues ever more salient. Workplace health promotion has become a commercial enterprise and care needs to be exercised about how it is advertised and what types of promises are being made by vendors. Vendors often present their programs as being simple, inexpensive, and effective for all types of employees. In this regard, the health promotion specialist may lose sight of the individual interests and expectations of the employees who participate in their programs. They may also ignore or underestimate the role of genetic, social, economic, and cultural realities as determinants of health.

Addressing and Minimizing Ethical Problems

DeJoy and colleagues [52] have offered a set of four recommendations for addressing ethical and legal issues in workplace health promotion programming, including disease management initiatives. First, sponsors of workplace health promotion programs and those implementing them should be well versed on the relevant ethical and legal issues. These topics should be an explicit part of the program planning process – not an afterthought. Second, workplace health promotion programs should adopt and disseminate formal operational policies and procedures. Employee rights and responsibilities should be specifically addressed as well as the mechanism or mechanisms for addressing conflicts or other problems. The European Network for Workplace Health Promotion [63] proposed criteria related to this recommendation. Third, open and two-way communication is critical to effective programming and widely acknowledged in benchmarking studies, programming guidelines, and discussions pertinent to building health cultures [64, 65]. And fourth, there should be opportunities for meaningful employee involvement at all stages of program planning, implementation, and evaluation. This involvement helps build trust, facilitates better and more timely problem-solving, and improves program participation.

Future Directions

There are a myriad of work-related trends that will continue to drive the growth of self-management programs in workplaces and may contribute to the advancement of self-management efforts beyond the workplace. These include an aging workforce, evolution of work away from a typical "worksite" and increased advances in technology.

As discussed in the introduction, the global population is aging, increasing the number of aged workers which are more likely to have chronic conditions. Additionally, more companies are hiring retirees to fill needed skill gaps that are not available in the current workforce [66]. This, coupled with the continued increase in the cost of healthcare, intensifies businesses motivation to embrace self-management programs.

An increasing number of workers are working from remote locations, a trend which has accelerated exponentially due to the COVID-19 pandemic [67]. Working away from the workplace places greater emphasis on the individual worker to manage their workload and health and well-being, requiring these individuals to set goals, problem-solve, make decisions, develop action plans, self-regulate, and monitor their progress – all self-management strategies / skills [2, 68]. There is a growing body of business literature that studies work-related self-management strategies and work performance [69, 70] with a number of similarities to self-management strategies for health. Younger workers in particular are looking for positions that provide flexible work arrangements and a greater emphasis on work-life balance, positions which will require advanced self-management skills. Hence employers are placing greater emphasis on those "soft" skills, which include goal setting, problem-solving, and self-motivation. Educational or training programs designed to train future workers should emphasize these skills.

Advances in technology will continue to drive business innovation, create new work arrangements, and place greater emphasis on self-management skills. Artificial intelligence has received considerable attention lately as being something that will transform the way we work. The ability to process large amounts of information quickly can increase work performance by helping the worker make better work-related decisions. The same technology can increase the individual's ability to make better health-related decisions. Wearables, devices worn by an individual that track a variety of biofeedback and activity measures (steps, blood pressure, calories, sleep, etc.), are becoming commonplace, having advanced from wristbands to watches, rings, cell phones, head phones, and even clothing. This continuous flow of data has definite health and well-being implications, and also implications for work as organizations are examining ways to use this information to increase work performance. The access of this data by employers also raises ethical issues discussed above such as privacy and confidentiality.

These workplace trends will continue to push self-management initiatives to embrace technology and explore new preventive directions, two trends already being incorporated in self-management programs.

Self-Management in the Digital Age

Use of the internet for providing self-management programs is not new, with a variety of programs being offered online. The CDSMP has been available online for a number of years (https://www.canaryhealth.com/bcbh-better-choices-better-health/) along with the Diabetes Self-Management and Arthritis Self-Management programs. Most vendors that provide healthcare services and/or health promotion programs for worksites have their own self-management program, with some utilizing CDSMP. These programs have been shown to be effective [2, 71, 72] but have largely been tested on older individuals in community-based settings. They have not been tested on employees or in a workplace context. Programs have been expanded to include mobile phone and/or tablet applications which have also demonstrated effectiveness [2, 73] in clinical or community-based settings and are currently being offered as part of the worksite programs. However, self-management in the digital age extends beyond individual programs.

Through the internet, individuals have greater access to data, information, and tools to support the management of their health than at any time in history. The expansion of electronic health records and patient portals have provided individuals with access to their own medical data and have increased the opportunity to partner with their medical provider in making informed decisions about their health [74]. Wearables allow individuals to monitor themselves daily, or even hourly, and this information can be downloaded and shared with their healthcare providers and/or compared with other participants via online app. All of this data can be combined into one database which, can be searched and analyzed. However, it is the interpretation and use of this data that is the most challenging for employees, particularly since not all information acquired online is accurate or relevant. Future worksite self-management initiatives must include some type of data literacy education which is designed to help individuals identify, work with, and understand relevant, accurate data and apply it to their health and well-being and balance privacy and confidentiality issues related to the availability and use of the data.

Preventive Self-Management

Twenty years ago, Glasgow raised the question, "Does the Chronic Care Model serve also as a template for improving prevention?," [75] which is a question we are still wrestling with today. Although self-management is only one component of the Chronic Care Model [76], it is the component that is most applicable to a variety of health behaviors. Although self-management is very discipline specific, many self-management programs address the implications of general health-promoting behaviors including physical activity, healthy eating, smoking, and alcohol use on the specific condition [33, 77]. Most individuals with chronic conditions must cope with multiple and interacting challenges (physical, psychological, and/or social) that need to be managed simultaneously. Individuals who have a better overall self-management ability will also be better able to achieve, maintain, or restore physical and psychological well-being [78]. Hence, there is a need for a multidimensional, inter-professional approach to self-management.

Health organizations such as the American Diabetes Association refer to this concept as lifestyle management and present it as a fundamental part of care. Lifestyle management not only includes self-management education and support but also focuses on nutrition, physical activity, smoking cessation, and psychological care [68]. Ultimately individuals may benefit more from broad self-management interventions that focus on the various factors that challenge overall well-being than those that focus on one problematic aspect of physical or psychological health [78].

There have been some worksite intervention studies that have supported this approach. Hendriksen et al. [79] tested a five-month intervention targeting self-management to perform healthy behaviors. A key element of the intervention was improving self-management with regard to individual vitality. The intervention included goal setting techniques, reflective counseling, and motivational interviewing by vitality coaches. It was hypothesized that by increasing self-awareness and knowledge of health practices, and stimulating ownership and responsibility for their actions, the employee would be able to improve their health behavior. This, in turn, would result in improved health and vitality, which would improve work performance and decrease presenteeism and sickness absence. The results showed significant improvement on vitality, work performance, sickness absence, and self-management of employees participating in the intervention [79].

Schopp et al. [77] examined the impact of a worksite self-management intervention titled "*Act Healthy*" that was offered as part of a WHPP. *Act Healthy* not only adapted elements of CDSMP but also incorporated the components of a social support intervention and an individually adapted health behavior change program. As such, it was targeted toward all employees, not just those with a chronic condition. The social support component focused on increasing healthy behaviors by strengthening social networks, while the health behavior change component emphasized setting goals, developing social support for the new behaviors and problem-solving around barriers. Participants in the intervention reported greater improvement in physical activity and energy, fewer depression symptoms, and that their health interfered less with their personal life and daily activities at follow-up [77].

This significantly expands the model of self-management from those who have a specific chronic condition to everyone who is healthy but wishes to manage their health and well-being. Can we identify a specific set of skills that could be taught to employees (or anyone for that matter) that would enable them to proactively manage their health, long before chronic conditions arise? If so, what supports can we put into place that would continue to support the employee's positive behaviors, without being too intrusive or disrupting of their professional or personal lives? This intriguing idea has not been widely tested in worksite settings, but this could have great promise for improving overall employee (and population) health and well-being.

Conclusions

Work organizations are critical partners in comprehensive efforts to prevent premature death from chronic disease. Adults who go to work are exposed to work factors and workplace social and physical environments that affect their health. Increasing prevalence of chronic disease in the workplace – due to growing numbers of older workers and increased prevalence of disease in employees of all ages – increases healthcare costs and decreases worker productivity. Such effects are associated with significant costs to the employer, employee, and the community.

Chronic disease self-management programs that teach employees skills to manage their condition and symptoms are important components of disease management. Such programs should be integrated into workplace structures and complement existing workplace health promotion programs. As is the case with workplace health promotion programs broadly, there will be challenges to implementation associated with lack of resources as well as ethical and legal considerations. Small- and medium-sized worksites are particularly challenged to allocate adequate resources for implementation and to carefully navigate issues of privacy and stigma. Additional work is needed to improve employee participation and program implementation and this information should be widely disseminated among all worksites, big and small.

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Chapter 11
Self-Management in Nutrition and Exercise

Stephanie Clookey

Introduction

The rising rate of chronic disease is a global crisis. One out of three adults will have more than one chronic disease in their lifetime, and chronic disease is responsible for three out of five global deaths [1]. In 2020, these rates are projected to rise, claiming responsibility for three-quarters of all deaths worldwide [2]. Chronic disease is costly, not only for human life, but also in terms of healthcare expenditures. Indeed, a near exponential relationship between healthcare expenditure and chronic disease has been observed, with expenditure doubling with each chronic condition gained [3, 4]. Compounding costs are characteristic of chronic diseases, increasing with years afflicted and disease severity [5]. Worsening matters, chronic diseases rarely occur in isolation, often manifesting or evolving into disease clusters [6]. For example, metabolic diseases such as obesity, diabetes, and cardiovascular diseases tend to cluster together, in addition to clustering with mental health disorders such as anxiety and depression [7–9]. The growing disparity between life expectancy and health span [10, 11] is deteriorating quality of life and putting healthcare systems on the brink of financial ruin.

The chronic disease crisis can be largely attributed to the global obesity epidemic and its associated comorbidities. In 2016, it was estimated that 39% of the world's adult population is overweight and 13% are obese [12]. In addition, 18% of the world's children between the ages of 5 and 19 were reported as overweight or obese, i.e., approximately 340 million children [13]. Higher body mass index is associated with comorbid illnesses, health complaints, and physical disability [14–16]. Obesity increases risk for diseases such as metabolic syndrome, type 2 diabetes, non-alcoholic fatty liver disease, cardiovascular diseases, and mental health disorders, to

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name a few [7, 9]. Furthermore, it is associated with increased risk for cardiovascular, cancer-related, and all-cause mortality [17].

Obesity and obesity-related diseases are largely preventable and treatable through healthy lifestyles, characterized by frequent physical activity, intentional exercise, and a healthy diet [2, 12, 18]. However, despite galvanizing calls to action from the World Health Organization (WHO) and other governing bodies, a majority of the global population is overconsuming, eating diets high in fat and sugar, and engaging in more sedentary behavior than ever before. This is due, in part, to industrialization, urbanization, and global marketization, which reduces energy expenditure from transportation, work, and leisure, as well as increasing the availability of highly palatable and caloric processed foods. Regardless of societal pressure to be thin [19, 20], the explosion of the diet and fitness industry [21, 22], and frequent weight loss attempts reported [23], the global obesity epidemic and its comorbidities continue to soar.

Improving health behaviors and ultimately addressing the obesity epidemic will require a multifaceted approach, consisting of both public policy changes and individual support. Tackling obesity and its related morbidities is an ideal target for the behavioral support available in self-management programs. Nutrition and exercise professionals have an opportunity to bridge the gap between physical activity and nutrition recommendations and actual behaviors. Rather than solely provide prescription, nutrition, and exercise, professionals should utilize self-management techniques within their professional practice. Unlike the traditional care model, self-management is problem-based and patient- or client-centered, and it aims to improve independence and self-efficacy. Self-management strategies can improve long-term client results, facilitate sustainable health behaviors, and teach clients how to autonomously prevent and manage chronic conditions. Increasing long-term success can improve the culture surrounding nutrition and fitness, play a critical role in disease treatment and prevention, and positively impact on global health.

Nutrition and Exercise for Disease Prevention

Advancements in science and medicine have traditionally aimed at treating and curing disease. However, this focus on disease treatment, rather than prevention, has paradoxically increased life expectancy, while failing to improve quality of life. The global health span, disease-free years of life, lags far behind that of life expectancy due to skyrocketing rates of chronic disease [10]. Disease prevention is crucial to productive advancements in both life expectancy and health span. Indeed, through observation of centenarians, those living to 100 years of age or more, it was observed that the most important aspect to a prolonged lifespan was not improved disease-coping or resilience, but rather the delayed onset of chronic disease. On average, centenarians live disease-free 18–24 years later than their shorter-lived counterparts [24]. For the majority of the population that has not hit the centenarian genetic lottery, physical activity is the lynchpin for advanced and optimized health span.

There is substantial evidence that physical activity prevents 35 different chronic conditions, such as, but not limited to, diabetes, obesity, metabolic syndrome, nonalcoholic fatty liver disease, anxiety, depression, and various cancers [18]. In 2018, Leskinen et al. conducted a study to quantify just how critical physical activity is for longevity. Utilizing a pool of over 40,000 middle-aged people between the ages of 50 and 75, they observed a clear dose response between self-reported physical activity and chronic disease-free life expectancy. On average, vigorously active men and women lived 6.3 years longer free of chronic disease than inactive individuals [25].

Despite the well-established benefits of physical activity, one in four adults do not meet the WHO's physical activity recommendations [26]. For adults, this means accumulating a minimum of 150 minutes of moderate or 75 minutes of vigorous aerobic activity per week, or an equivalent combination with a minimum duration of 10 minutes. For optimal health, it is recommended to perform 300 minutes per week of moderate or 150 minutes of vigorous aerobic activity, with muscle strengthening activities two or more days per week [26]. However, the benefit threshold of exercise has been shown to be three to five times higher than the WHO recommendation, with no deleterious effects of physical activity observed at even 10 times the recommendation [27].

The global rise in obesity is indicative of the population's difficulty adhering to a healthy diet and is an ideal target for a self-management strategy. According to the WHO, a healthy diet consists of maintaining energy balance through consumption and expenditure, and is abundant in fruits, vegetables, legumes, nuts, and unprocessed whole grains, while minimizing excess salt, sugar, and saturated and trans fats [28]. Diets such as the Mediterranean diet, the DASH diet (Dietary Approaches to Stop Hypertension), and other plant-based diets, which fulfill these recommendations, are associated with lower risk of cardiovascular outcomes and intermediate risk factors, such as high cholesterol, triglycerides, fasting glucose, blood pressure, and body weight [29]. They also decrease the risk of obesity, diabetes, cognitive decline [30], and cardiovascular disease [31].

The WHO recommends 400 g of fruit and vegetables, approximately five servings, per day [32]; however, a majority of people fail to meet these guidelines [33–36]. Global fruit and vegetable consumption varies widely; however, rates of inadequate intake by country ranges from 60 to over 90% of adults [37]. Notably, in the United States, only one in ten adults consumes adequate quantities of fruits and vegetables [34], and in Eastern Europe, it is less than 8% of the population [37].

Poor diet and sedentary behavior are wreaking havoc on health and healthcare systems around the world, inspiring a paradigm shift in healthcare that emphasizes both treatment and the prevention of disease, as well as empowering strategies such as self-management. The rising rates of chronic disease demand greater involvement of nutrition and exercise professionals as part of the healthcare teams to promote wellness and aid in disease management, as they have the education, experience, and contact frequency to bridge the gap between recommendations and behaviors.

Nutrition and Exercise for Disease Treatment and Management

Diet and exercise do not only prevent disease onset but also are effective therapeutic elements for a variety of diseases. For the purposes of this chapter, the discussion is limited to the role of lifestyle in curing metabolic diseases, as the obesity epidemic is arguably the main driver of increasing global chronic disease rates and most pertinent to the nutrition and exercise professional using self-management interventions with clients. However, there is substantial evidence for utilizing lifestyle changes as medicine for a variety of diseases; for example, Pederson et al. have described the utilization of exercise as a therapeutic aspect for 26 different diseases [18]. Similarly, dietary intervention is also a common therapeutic and preventative measure for a number of diseases, such as cardiovascular disease, diabetes, gastrointestinal diseases, and cancer, to name but a few. This portion of the chapter will touch on the burden of these chronic diseases and the efficacy of using lifestyle interventions as a therapeutic measure, with the intent to illustrate the critical role nutrition and exercise professionals play in the resolution of the chronic disease crisis, and the dire importance of using techniques such as self-management to facilitate sustainable behavior change. Special considerations and exercise prescriptions for these various diseases will not be discussed, though they have been discussed in length elsewhere, such as the *American College of Sports Medicine Guidelines for Exercise Testing and Prescription*; it is highly recommended that all nutrition and exercise professionals seek out such valuable resources.

Metabolic Syndrome

Metabolic syndrome is a cluster of metabolic disease risk factors with a strong behavioral component, suggesting it is an ideal target for self-management. Metabolic syndrome is defined as having three or more risk factors, including abdominal obesity, high triglycerides, low- and high-density lipoprotein cholesterol, high blood pressure, and elevated fasting blood glucose [38]. Metabolic syndrome is often a precursor to metabolic diseases such as cardiovascular disease and type 2 diabetes. Within the last 10 years, the prevalence of metabolic syndrome has been estimated in various regions. Estimations include 25% in the Middle East [39], 24.5% in mainland China [40], 40% in Portugal [41], and 33% in the United States [42]. Metabolic syndrome is harder to measure than other diseases. However, based on epidemiological data, it is around three times more common than diabetes, and thus, the global prevalence is estimated to be about one-quarter of the world population [43]. When metabolic syndrome is identified, intervention using self-management may prevent progression to diabetes.

Management of metabolic syndrome through doctor's visits and pharmacological treatment is a burden to healthcare systems. In the United States, Boudrea et al. conducted a study comparing the health utilization and costs for persons with and without metabolic syndrome. Over the two-year study period and over 170,000 participants, they observed that those with metabolic syndrome had 1.6 times greater annual healthcare costs than those without. The total costs per person increased by an average of 24% per additional metabolic risk factor acquired [44].

Diet and exercise are important components for the prevention and treatment of metabolic syndrome [45]. Diet and exercise have been shown to improve metabolic syndrome risk factors such as fasting insulin, fasting glucose, systolic blood pressure, high density lipoproteins, triacyl glycerides, and body mass index [46]. Exercise and regular physical activity increase energy expenditure and improve insulin sensitivity. In addition to maintaining energy balance to prevent obesity, healthful diets can effectively treat and prevent the advancement of metabolic syndrome into type 2 diabetes or cardiovascular disease [47, 48].

Obesity

According to the WHO, adult obesity prevalence has tripled since 1975, and child and adolescent obesity has quintupled. In 2016, it was estimated that 39% of adults and 18% of children were obese worldwide [12]. The obesity epidemic doesn't appear to be slowing down anytime soon; based on current trends, the number of overweight and obese individuals are projected to be 2.16 billion overweight and 1.12 billion obese people worldwide by 2030 [49].

Simply put, obesity is a condition characterized by excess fat accumulation directly caused by overconsumption. However, the true origin of the behavior responsible for obesity is multifactorial and complex, with biological, psychological, economic, and socio-cultural influences. Obesity is troublesome for both patients and the healthcare system, as it is accompanied by comorbidity and disability. Obesity is a major risk factor for other chronic diseases such as, but not limited to, non-alcoholic fatty liver disease (NAFLD), type 2 diabetes, cardiovascular disease, cancer, osteoarthritis, and sleep apnea. In a systemic review by Withrow and Alter, it was estimated that an obese individual's medical expenses are 30% higher than those of normal-weight individuals [50]. Self-management can improve adherence to nutrition and exercise interventions, which can facilitate weightloss through reductions in caloric intake, and increases in expenditure. These efforts should be accompanied by psychological support through motivational interviewing, cognitive behavioral therapy, etc. In some cases, pharmaceutical assistance may be necessary.

Type 2 Diabetes

Diabetes is one of the four most common non-communicable chronic diseases (cardiovascular disease, cancer, chronic respiratory diseases, and diabetes). In 2016, diabetes was the direct cause of 1.6 million deaths. It is a major cause of blindness, kidney failure, heart attacks, stroke, and lower limb amputation [51]. Approximately 90% of diabetics have type 2 diabetes [51, 52]. In just 30 years, type 2 diabetes has risen from the 18th leading cause of death to the 9th [53]. In 2017, approximately 462 million individuals have type 2 diabetes, approximately 6.28% of the world's population [53]. It is projected that the economic burden of type 2 diabetes will increase from 1.8% in 2015 to 2.2% of the global GDP by 2030 [54].

Type 2 diabetes is one of the fastest growing diseases globally. However, regular exercise and a healthy diet can effectively prevent, slow, and manage the disease. Indeed, lifestyle interventions have outperformed pharmacological interventions such as metformin in the reversal of prediabetes, reducing the incidence of diabetes by 58% [55]. Modest reductions in body weight (5–10%) can substantially improve glycemic control [55, 56], and attaining and maintaining a healthy body weight are treatment goals in diabetics who are overweight or obese [57]. In addition, lifestyle interventions manage glycemia, blood pressure, and blood lipids to reduce the risk of micro- and macro-vascular complications associated with the disease [58].

In addition to facilitating weight loss, healthy diets have been shown to improve glycemic control, prevent metabolic syndrome, and reduce cardiovascular risk factors [59]. Similarly, regular exercise has been shown to improve metabolic dysregulation and induce anti-inflammatory effects in diabetics [60]. Aerobic exercise can reduce visceral adiposity in diabetics [61], and both aerobic and resistance training can lower HbA1C [62] as well as other markers of insulin resistance, such as fasting insulin, fasting blood glucose, and HOMA-IR scores [63].

Cardiovascular Diseases

Cardiovascular disease is the leading cause of mortality and morbidity worldwide [64, 65] and is responsible for one-third of all global deaths [1, 66]. Over 95% of all cardiovascular disease-related deaths are attributable to six main conditions: ischemic heart disease, stroke, hypertensive heart disease, cardiomyopathy, rheumatic heart disease, and atrial fibrillation [66]. There is strong epidemiological and clinical data to support the therapeutic role of exercise in cardiovascular disease [67–69]. There appears to be a dose-dependent association between high physical activity and reduced risk of cardiovascular disease and mortality. This relationship has been observed in over 130,000 individuals, across 17 different countries of various income levels and irrespective of modality (work or leisure) [70]. Exercise can decrease the incidence of traditional cardiovascular disease risk factors, such as hypertension, dyslipidemia, and diabetes mellitus, and can protect against the formation of intraluminal blood clots [67, 69]. Furthermore, there is increasing evidence that exercise has antiatherogenic effects in blood vessels, maintains autonomic balance, provides cardioprotection against ischemia–reperfusion injury, stimulates myocardial repair, and staves off sarcopenia [69]. Adherence to health behaviors, such as abstaining from smoking, maintaining a BMI < 25, engaging in regular exercise, eating a healthy diet, and consuming alcohol in moderation, all common targets of self-management, has been shown to reduce coronary events by 62% over 16 years in a cohort of 42,000 adult men. Furthermore, men who adopted at least two of these behaviors had 27% lower risk for cardiovascular events compared to those who did not [71].

Nonalcoholic Fatty Liver Disease

Nonalcoholic fatty liver disease (NAFLD) encompasses a spectrum of liver diseases, ranging from simple steatosis to steatohepatitis with varying degrees of cancer and cirrhosis of the liver. It is the leading cause of liver disease, reaching every continent and impacting on 24% of the population [72]. For reference, it is estimated that there are currently 64 million people with NAFLD in the United States and 52 million in Europe [73]. In 2016, the annual economic burden of NAFLD was estimated to be $103 billion in the United States and €35 billion in Europe [73].

Lifestyle interventions are currently the only methods of prevention and treatment for NAFLD, and they are extraordinarily effective. Weight gain and obesity are the leading risk factors, with common comorbidities being obesity, metabolic syndrome, and type 2 diabetes [72, 74]. For NAFLD patients, weight reductions of 10% can induce a near universal non-alcoholic steatohepatitis resolution and fibrosis improvement by at least one stage [75], as well as a > 80% reduction in accumulated liver fat [76]. Diet, physical activity, and intentional exercise can create and facilitate the caloric deficit required for weight loss.

In addition to facilitating weight loss, improvements in food quality and incorporation of exercise can improve NAFLD prognosis. Incorporation of intentional exercise, even in the absence of weight loss, can induce 20–30% reduction in intrahepatic lipid [77]. Diets rich in polyunsaturated fats and omega 3 fatty acids may reduce intrahepatic fat content and steatosis [78]. Even with overconsumption, a diet high in polyunsaturated fats, in comparison to saturated fat, reduces intrahepatic lipids [79]. Furthermore, the Mediterranean diet has been shown to decrease risk for cardiovascular disease [80] and diabetes [81] and reduce liver fat in overweight NAFLD patients [82, 83].

Depression and Anxiety

Healthy diet and exercise are necessary for the maintenance of mental health and well-being. Relative increases in maximal cardiorespiratory fitness and habitual physical activity are cross-sectionally associated with lower depressive symptomatology and greater emotional well-being [84]. Healthy eating and the maintenance of a healthy body size are protective against mental health disorders such as anxiety and depression. Indeed, there appears to be a reciprocal link between obesity and depression, in that obesity increases the risk for depression and depression also increases the risk for obesity [7]. Depression also has comorbidities with other metabolic diseases such as type 2 diabetes, metabolic syndrome, and cardiovascular disease [85].

Exercise is a viable treatment option for those with depression and anxiety, as it can improve health, body image, coping strategies, and quality of life. Exercise has produced comparable improvements to antidepressant medication and psychotherapy in patients with mild and moderate depression. For those with severe depression, it has been shown to be a valuable complement to traditional therapies [85, 86]. Even low-intensity exercise, such as flexibility exercises, has been shown to reduce suicidal ideations in those with major depressive disorder [87]. Exercise is also effective in the treatment of clinical anxiety, though it appears that higher intensity options are more effective than lower intensity options [88].

Global Contributions to Obesity and Chronic Disease Crisis

The rise in industrialization, urbanization, and global marketization created an undeniable global shift in health. As the global community increases its wealth, micronutrient deficiencies, malnutrition, and infectious diseases are fading into the background as the world's greatest public health issues. The obesity epidemic and the subsequent rise in non-communicable chronic diseases have emerged at the forefront of global concern as a result of the dramatic lifestyle changes.

Advancements in technology have created labor-saving equipment for economic work (robotics, assembly lines) [89], transportation (trains, cars, etc.) [90], the home (microwaves, mixers), and recreation (television, cell phones, etc.) [90]. The convenience technology has subsequently reduced daily physical activity, creating a populace more sedentary than ever. Similarly, urbanization and advancements in agriculture have facilitated overconsumption and global increases in body mass, one of the top five risk factors for attributable disease [91]. Technological advancements in agriculture have increased food availability and processing.

Urbanization has resulted in more people purchasing rather than growing their food and has created occupations incompatible with traditional responsibilities such as home food preparation, child care, and elder care [92]. Urban proximity has increased access to pre-prepared food from restaurants, fast food establishments, and pre-packaged foods. In addition, the commercialization of food has led to increased food marketing, distribution, and sales. In response to consumer demand, highly processed, convenient food options now flood the market. In order to increase palatability, lower costs, and increase shelf life, these foods are often highly caloric with low nutrient density. The agricultural revolution has increased availability of cheap vegetable oils, sugar-sweetened beverages, and animal source food consumption; as a result, people are overconsuming while neglecting to ingest high-quality food sources, such as fruits and vegetables [93].

The shift in global culture in conjunction with our evolutionary biology was the perfect storm for the obesity and chronic disease epidemic we are experiencing today. As a species, we have acquired various traits that have historically enabled our survival. For example, humans have strong preferences for both sweet [94] and fatty foods [95]. Our thirst and hunger mechanisms are not linked, meaning that calories ingested from liquids do not induce feelings of satiety. Lastly, we have an innate desire to eliminate or reduce physical exertion to prevent unnecessary energy expenditure. These adaptations are conducive to fat preservation and gain for survival in famine; however, with the evolution of cheap caloric sweeteners, food processing, highly available oils, and energy saving technology, they are, in part, responsible for the obesity crisis [96].

Since returning to pre-industrialized times and giving up technology are highly unlikely, the global community is in dire need of a cultural revolution involving more intentional dietary choices and volitional exercise. Exercise professionals need to be aware of both the aforementioned environmental and biological hurdles to healthy lifestyle choices and to master behavior change technologies such as self-management to counter these challenges.

Current Approaches to Improving Obesity and Wellness Behaviors

In parallel to the rising rates of chronic disease, inactivity, and obesity, the fitness industry has paradoxically experienced tremendous growth over the last decade, with over 50% growth in revenue between 2007 and 2018 [97]. In 2017, the global wellness economy was estimated at $4.2 trillion US dollars. Within this market, recreational physical activities generated 44% or $367.7 billion on activity participation [97]. Despite the economic success of the private fitness industry, the Global Wellness Institute estimates that only 33% of the world participates in sports and recreation, and only 3% are members of fitness facilities or regularly participate in structured or independent exercise [21]. This conclusion is similar to that of the WHO, which estimates that one in four adults do not meet the physical activity guidelines [26]. Regardless of differences in numerical estimations, the conclusion remains the same: the world is inactive and regularly overconsuming, despite increasing access.

There are two necessary approaches to addressing inactivity and overconsumption. The first is through public health policy and government initiatives. For example, self-management interventions can be added to the roster of paid services by healthcare and government third-party payers. Despite many governing bodies providing recommendations and urging improvements in health behaviors, no nation has designed and implemented a comprehensive policy that addresses the various influences on obesity such as behavioral support, agriculture, retail, education, trade, and economics [98]. There are numerous barriers to making these policy changes. In the spirit of commercialism, governments are hesitant to infringe on personal choice [98, 99], the large and influential food industry is driven by profit rather than public health initiatives [100], and the uncharted nature of the obesity epidemic renders no evidence-based model. However, common recommendations for regulations and initiatives include increased access to safe and free places to be physically active such as parks, recreational, and outdoor amenities [101, 102], providing infrastructure that facilitates more movement in our daily lives, addressing issues of access to healthy food (i.e., food deserts) [103], and imposing taxes or incentives to improve dietary choices [104]. Improvements in infrastructure and public policy are undeniably powerful tools that should be utilized [101, 102].

Although government involvement is important, the greater challenge is creating a cultural revolution surrounding nutrition and exercise through self-management strategies that allow patients/clients to take charge of their own health. The need for a change in culture is emphasized in the Nutrition Transition Model and is a central focus within the WHO [92, 96, 105]. Psychosocial factors are the major barriers to adopting health behaviors. Based on research and survey review, the Global Wellness Institute reports the top four barriers to regular exercise: lack of time, lack of interest, physical or health conditions, and lack of motivation [21]. These perceived barriers have been consistently reported in a number of studies, across numerous countries and demographic groups [102, 106–108]. All of these barriers are predominantly psychological, rather than physical barriers. With regard to ability, exercise comes in various modalities, and experienced exercise professionals are trained to modify exercise prescriptions around individual needs. As for a lack of time, this barrier is usually more indicative of lack of prioritization than scheduling conflicts [109]. In fact, thanks to the industrial revolution, in many places, such as Europe and North America, where >30% the population is obese [110], people have more time than ever before. Time spent working in these countries has experienced precipitous decline, with citizens spending significantly less time working today than they did in the 1960s [111].

One way that we can facilitate a widespread cultural shift surrounding health behaviors is to improve the quality of care provided by nutrition and exercise professionals, thus increasing individual success. In many parts of the world, the fitness industry is booming [21], there is a culture obsessed with beauty and thinness [112], yet obesity is still on the rise. It is short-sighted to believe that the general population, largely overweight and obese, are uninterested in reducing body fat and improving their fitness or that they are unaware of the health consequences associated with sedentary behavior and poor nutrition. Not only are people aware and interested, but many are actively trying, and struggling, to improve their condition, and self-management skills can be a boon to these motivated individuals. Public survey data indicates that the average person will have numerous weight loss attempts throughout their lifetime. In the United Kingdom, a poll of 2000 citizens reported trying two diets per year on average, leading to projections of 126 diets in their lifetime [113]. Similarly, US federal survey data in 2016 revealed that 42% of citizens reported weight loss attempts [114]. In 2017, Santos et al. conducted a systematic review and meta-analysis to estimate personal weight control attempts worldwide. Utilizing 72 studies, they estimated that 42% of the general population has attempted significant weight loss. Broken down by geographical region, they estimated that the percentage of the population that has engaged in weight loss attempts are 16.6% in Africa, 33% in East Asia and the Pacific, 31.7% in Europe and Central Asia, 26.6% in Latin America and the Caribbean, 26.8% in the Middle East and North Africa, and 44% in North America [23]. Reflective of these attempts is the global weight management market, which is booming. It has a net worth of US $189.8 billion and is projected to reach a value of US $269.2 billion by 2024 [22].

It is evident that the public struggles to find success adopting and adhering to diet and exercise guidelines and could benefit from interventions that support skill-building. The aforementioned global environment changes in conjunction with the commercialization of nutrition has caused consumers to be inundated by dietary supplements, fad diets, and misleading food marketing, thus creating a dire need for increased food and dietary literacy within the population. Thus, one component to increasing individual success with lifestyle changes may include increasing public knowledge on what constitutes healthy nutrition and sufficient exercise, as studies have shown a high variability of public opinion regarding what foods are considered healthy [115]. Nutrition knowledge has been shown to be a partial mediator for fruit and vegetable intake in the general population [116], and nutrition education interventions have successfully increased fruit and vegetable intake in overweight and obese subjects, years after the intervention [117]. Greater nutrition education has been shown to facilitate improved weight loss outcomes in overweight or obese individuals [118]. Education interventions can improve not only individual diet [119] but also the lifestyle and dietary choices of families. In the United States and Japan, maternal nutrition education interventions have been efficacious in improving diet quality in their preschool-aged children [120, 121]. This may be particularly pertinent considering the rising rates of childhood obesity [13, 121].

Although education is undeniably an important tool, improvements in health literacy are not always associated with weight loss or intervention engagement [122], highlighting the need for interventions such as self-management to bridge the gap between knowledge and intentions, on the one hand, with skills and behaviors on the other. The belief that improving nutrition knowledge alone is sufficient to change nutrition and exercise habits oversimplifies the obesity epidemic and behavioral psychology. Human behavior is multifactorial and complex. There are various social and psychological influences on behavior which are unique to each individual, such as perceived consequences, attitudes and beliefs, environmental influencers, and various internal motivators [123]. In 2010, a systematic review by

Guillaumie et al. concluded that the most consistent predictors of fruit and vegetable consumption after educational interventions were motivation and goals, beliefs about capabilities, consequences, social influences, and, lastly, knowledge [124]. These findings support the notion that competence and knowledge are only a piece of the puzzle.

Individual nutrition *interest* has been shown to strongly mediate health-seeking behaviors, reading of food labels [125], and ultimately dietary choices [126], and a key component of self-management strategies is learning health and nutritional information in support of one's goals. Consumers are seemingly less interested in nutrients and nutrition science and more interested in what food selections will help them reach their personal food goals. This probably explains the discrepancy observed between what nutritionists and consumers believe should be on food labels [127] and the high variability of public opinion on what constitutes healthy food [115]. For many, making meaningful change requires individualized support, based on individual motivations, desires, and needs. An educated nutrition and fitness professional who can translate nutrition and exercise science and help design appropriate strategies for individual goals is an excellent resource in self-management programs.

Self-Management in Nutrition and Fitness

Although self-management has been traditionally utilized for chronic disease management, conducted by a facilitator or co-facilitators in a group setting, the principles of self-management can be an effective strategy for increasing health behaviors and preventing or managing chronic diseases within the field of nutrition and exercise. Although nutrition and exercise professionals typically work with patients/clients on a 1:1 basis (physical therapists, dietitians, personal trainers, etc.), group self-management skills and principles can be adapted and utilized to improve 1:1 client outcomes and facilitate long-term behavior change. The core skills of self-management include problem-solving, decision-making, resource utilization, forming of a patient/healthcare provider partnership, and taking action; all these principles function to increase self-efficacy. This section will discuss these various principles and their application in a nutrition and exercise setting.

Forming a Client/Professional Partnership

Utilizing self-management would incite a fundamental change in the professional culture of nutrition and exercise. Although personal relationships and building rapport are integral to the profession, the traditional care model establishes the professional as the expert and the client is expected to be adherent to expert recommendations. This methodology can work well for highly motivated athletes and clients with established health habits. However, it can be a frustrating and disappointing cycle of non-adherence for those trying to make major lifestyle changes. Unlike the traditional care model, the self-management model is centered around the client's problems, concerns, and interests, and functions to empower the client to have extreme ownership over their own health and fitness. This model establishes the professional merely as a resource at the client's disposal, who serves to provide education and skills for them to navigate their own journey.

The juxtaposition between models may be jarring for longtime professionals; however, there is clinical and theoretical evidence for the humble transition to a client-powered approach. This approach is rooted in self-determination theory, which suggests greater adherence to autonomous behavior, as opposed to controlled or coerced. Fueled by internal motivation, self-management is more effective than coerced behaviors with extrinsic motivation. According to self-determination theory, practitioners should support the process of internalization through facilitating autonomy, competence, and relatedness [128]. This is relevant for nutrition and exercise professionals, as changes in health behaviors are largely extrinsically motivated in nature. For example, clients may seek out a professional because their physician told them they need to eat better or exercise more, they want to improve their aesthetics, or manage a disease. For this reason, professionals should be open to adopting a more flexible approach to nutrition and exercise prescription, placing a greater emphasis on finding exercise modalities and eating practices that are inherently pleasing or of interest to the client. In addition, there should be an emphasis on building a partnership, and professionals should utilize autonomy-supporting behaviors during client counseling, such as eliciting and acknowledging client perspectives, explaining the rationale for advice, providing various options and strategies, and minimizing control and judgment [129]. If appropriate, nutrition and exercise professionals may consider expanding the scope of conversations to other domains of wellness that may be barriers to nutrition and exercise or of client concern, such as sleep and stress management.

Facilitating autonomy through this partnership results in greater client effort, engagement, and persistence [128] and, thus, will produce better client outcomes. Higher autonomous regulation and greater perceived support have been shown to improve patient outcomes in a number of studies and populations such as increased weight loss in obese, male subjects diagnosed with metabolic syndrome [130], and increased physical activity, and weight loss maintenance in women weight control interventions [131]. Clients who feel greater autonomy and support often illustrate greater adherence to weight loss or maintenance programs [130, 131] and physical activity interventions [131].

Managing Personal Bias

As previously discussed, facilitating long-term behavior change in nutrition and exercise requires successful relationship building. In order to do so effectively, professionals must be empathetic, open-minded, and humble enough to continuously evaluate their own internal biases. Internal biases may tempt us to make assumptions about clients, their goals, or their health, which can negatively impact on client relationships and outcomes. All professionals should be acutely aware of how internal biases on race, gender, sexuality, age, etc., may influence their quality of care. For the nutrition and exercise professional trying to foster long-term behavior change and reduce chronic disease, it is especially pertinent to be aware of weight stigma. No matter how well intentioned, one should not assume fitness or health based on body appearance or fatness, nor goals based on current body physique. Every fitness professional should be educated on the benefits of exercise and healthy eating even in the absence of weight loss, as well as the presence of metabolically healthy obesity [132]. Furthermore, they should restrict their advice solely to the requests and goals of the client.

Overweight and obese individuals are often falsely assumed to be lazy, gluttonous, and weak-willed [133]. This stigma produces prejudice and bias and results in reduced quality of care and impaired client-centered communication. It fosters nonadherence, mistrust, and ultimately results in worse outcomes for weight loss and mental health [134]. The chronic stress associated with stigma has long-term consequences that may add to risk for cardiovascular disease, stroke, anxiety, and depression [135, 136]. Unfortunately, weight stigma is present across all disciplines, with nutrition and fitness being no exception. Weight stigma has been observed in various careers within the field, including dietitians and nutritionists, physical therapists, physical education, and fitness professionals [137]. Self-management groups foster supportive group dynamics, which can help minimize stigma as a barrier to change.

Increased awareness and sensitivity to weight stigma will improve relationships and effectiveness. Professionals should be mindful that discrimination makes fitness or healthcare facilities intimidating or unwelcoming for many who are overweight or unfit. Professionals should be sensitive to environmental factors that may cause unnecessary humiliation or isolation, such as accessibility of certain machines or exercises that may not be conducive to larger body sizes. They should be empathetic that clients may be ashamed or embarrassed by dietary habits, or feel sensitive to the way professionals pose questions. Qualitative analysis of successful weight loss and long-term improvements in physical activity showed that environments where individuals felt safe, accepted, and encouraged were extremely important for long-term commitment to weight loss and successful lifestyle changes [138]. Self-management engenders respect for an individual's autonomy and its goals are inherently self-determined, underscoring the value and right of participants to address their own health priorities regardless of other people's or society's opinions. It is the responsibility of the nutrition and exercise professional to foster that type of environment through building a healthy, supportive partnership, and self-management tools can help.

Problem-Solving

Self-management is problem-solving in nature. Similarly, nutrition and exercise professionals are often engaged to help solve problems such as poor fitness, weight gain, difficulty achieving an athletic goal, high cholesterol, chronic pain, or disease prevention, to name but a few. However, as previously mentioned, many of these problems may be extrinsically motivated or encouraged by their physicians, family members, or society. Unfortunately, external pressure is inadequate for long-term commitment and sustainability [139]. Thus, it is recommended to utilize motivational interviewing skills to resolve resistance or ambivalence to behavior change, as well as understand the meaningful problems and motivators to the client. Motivational interviewing, characterized by reflections and open-ended questions while avoiding confrontation, has been shown to be an effective strategy for facilitating major health behavior change, such as substantial weight loss in overweight or obese individuals [140, 141] as well as managing chronic pain and other diseases [142].

Self-management calls on individuals to define and pursue goals meaningful to them and can be supplemented by other effective behavioral strategies. For example, the goal of motivational interviewing is for clients and practitioners to select problems that are particularly meaningful to the client, more immediate, and more specific than general goals such as improvements in health. Identifying and selecting meaningful problems will greatly improve client adherence, as goal priority has been shown to significantly moderate health behaviors [143]. Professionals should guide and help clients understand how improvements in nutrition and fitness can influence their everyday lives through the resolution of problems or the creation of opportunities. This tactic is supported by the findings of Rhodes et al., where it was observed that physical activity behavior, when related to other life goals such as facilitation or conflict, has greater association with behavior change than more general, high-level objectives such as improvements in health [144].

Decision-Making

Traditionally in self-management, decision-making skills are utilized to navigate the ever-changing, day-to-day landscape of chronic disease, such as knowing when symptoms are medically serious or how to manage medications. Similarly, maintenance of lifestyle changes in nutrition and exercise also require this skill. Rather than solely giving exercise programs or meal plans, professionals should teach clients the foundational knowledge and decision-making skills to independently navigate various situations and deviations from normal routine. For example, clients may need to know how to maintain their exercise routine at home with limited equipment or how to work toward a weight loss goal while eating out at restaurants. As previously discussed, education and competency are important components to lifestyle changes, as they have been shown to mediate health behaviors [116, 117] and improve outcomes in health behavior interventions [118, 119].

To build decision-making skills, professionals should discuss anticipated or past barriers to behavior change and possible solutions during client counseling sessions. Forecasting hurdles and resolutions has been shown to improve health behaviors, and thus clinical outcomes, across a variety of medical conditions and income levels [145]. When fostering these skills and strategies, professionals should teach clients to view success as a spectrum and make compromises, rather than engage in dichotomous thinking. Rigid dietary or exercise strategies should not be encouraged, and behaviors should not be appraised as "good or bad" or "successful or not" (i.e., a weight loss pursuit isn't ruined, nor did the client fail because they ate a piece of cake). Dichotomous thinking, or "all or nothing mentality," is unsuitable for healthy, sustainable behavior change and is characteristic of maladaptive eating patterns such as eating disorders [146] and obesity [147, 148]. In order to facilitate long-term, meaningful change, nutrition and exercise professionals need to give their clients the knowledge and tools for independent decision-making and teach self-compassion and flexible thinking for navigating setbacks.

Resource Utilization

The third self-management skill is resource utilization. With the explosion of fitness technology and the increased need for healthier communities, the resources available for nutrition and fitness are bountiful, but not all are necessarily helpful nor scientifically based. Nutrition and exercise professionals have an opportunity to serve as science liaisons in the discussion of fad diets, dietary supplements, and exercise myths. They should also discuss the evidence-based tools and resources clients may want to employ during their health and fitness journey.

The most helpful resources are tools that aid in self-monitoring and/or facilitate health behavior adherence. Persuasive technologies, such as sensors, wearable technology, mobile and handheld devices, web and social networks, and games, have been shown to be effective in facilitating health behavior change [149]. Self-monitoring technology can also improve healthy eating and physical activity [150]. Using technologies such as fitness trackers, food logs, and body weight scales as a means of self-monitoring has been shown to be a significant predictor of successful weight loss [151] and improvements in health behaviors [152]. Many of these monitoring tools and behaviors, such as self-weighing, have been shown to be beneficial for weight maintenance [153, 154] with no reports of adverse psychological effects in healthy populations [154]. Specifically, self-monitoring via fitness and food log applications on smartphones is showing increasing promise; smartphone applications increase the convenience of diet and exercise logging [155] and have been shown to improve daily physical activity [156, 157] and dietary adherence during weight loss interventions [158].

In addition, there are basic skills and resources clients should be taught, such as where to get reputable nutrition and fitness information, how to read food labels, how to estimate portion sizes, how to utilize healthy cooking practices, make recipe modifications, gauge exercise intensity, warm up and cool down adequately, etc., all of which will facilitate independence. Nutrition and exercise professionals are trained to provide these skills and resources, and self-management focuses on client efforts to manage such health resources in support of individual goals.

Taking Action

After finding meaningful goals and providing education on resources and decision-making, clients can create action plans with supportive nutrition and fitness professionals. Action plans are frequently reviewed, and established 1- to 2-week-long behavioral strategies help clients meet their goals. Unlike prescriptions, action steps are focused on independent health behaviors. Health behavior change is most effective when behaviors are self-directed and self-regulated [159]; thus, the client should be the primary author of the action plan. The role of the nutrition and exercise professional is to provide support and education for the client, so the client can make attainable action steps relevant to their goals. For example, if the client's goal is to lose weight, then they must be taught the principles of energy balance, as well as healthy and reasonable strategies to create an energy deficit, and must be supported in learning to refine action steps to reach this goal.

Initially, professionals should encourage clients to develop action plans and select behaviors that are inherently enjoyable or will provide some immediate gratification. For example, if an exercise professional has a sedentary client who hopes to exercise an additional day independently, they should encourage a modality of exercise that is social or pleasurable in some way, such as planning a walk with a friend. This strategy will help build confidence and positive associations with these new lifestyle behaviors.

In some cases, it may be appropriate to expand the scope of action plans to address a wider range of health behaviors that may interfere with nutrition and exercise goals, such as stress management and sleep. Poor stress management and emotional regulation can negatively impact on motivation to exercise [160, 161] and may elicit undesirable behavior such as emotional eating [162, 163]. Similarly, inadequate sleep can negatively impact on mental and physical health, physical activity, and exercise behavior, as well as facilitate hedonic eating [164] and overconsumption [165]. Addressing these issues may require providing resources and education or recommending the guidance of other healthcare professionals.

Ultimately, all action plans should be seemingly very easy and attainable. As per traditional self-management, assessment of confidence should be conducted prior to committing to the week's action plan, and clients should feel capable, giving a rating of a 7 or higher out of 10 on the confidence scale to ensure that the goal is both valued by the client and seen by the client as feasible. This often involves action plans that consist of small compromises or additions rather than radical changes. Using the example of weight loss, perhaps an action plan that requires giving up all takeout and fast food seems intimidating and nearly impossible! However, the client may find it exceptionally easy to switch from sugar to a zero-calorie sweetener in their morning coffee. Of course, both strategies will aid in the creation of a caloric deficit, but the strategy that feels simple and within reach is far more likely to be utilized and maintained.

These self-management strategies are recommended to ensure client success. This is of utmost importance, as initial, perceived success has been shown to produce significant improvements subsequent to success [166]. For this reason, it is critical that the professional not only helps the client develop an appropriate action plan but also provides support and positive social feedback for client efforts. If the client is unable to adhere to the action plan, professionals should prevent feelings of shame or guilt and focus on modifying or establishing a new plan.

Other Considerations

Facilitating Positive Client Experiences

Nutrition and exercise professionals should be mindful that prior to soliciting your professional guidance, clients have likely made many previous attempts to improve diet and exercise habits. Improving health behaviors is difficult, not only because of the societal and biological barriers, but also because initially, these changes are unpleasant in nature. For untrained individuals, exercise can be uncomfortable and produce significant muscle soreness. In addition, all humans have an innate preference to minimize energy expenditure and ingest highly caloric foods [94, 95]. Food preferences develop early in life [167], are heavily influenced by parents [168] and socio-cultural factors [169], and are difficult to change.

People naturally engage in reinforcing behaviors, and reinforcements largely influence our behavior [170]. Thus, professionals should be mindful of modifications and strategies that can minimize unnecessary negative experiences and facilitate positive ones. For example, exercise prescriptions should be of appropriate exercise volume, intensity, and skill level to minimize injury risk and extreme muscle soreness, and dietary changes should be gradual. Lastly, the environment should be welcoming and non-judgmental. Professionals should be empathetic and use their knowledge and skills to ease clients into their lifestyle interventions.

Managing Expectations

Another important component to facilitating long-term behavior change is expectation management. This may come in the form of managing expectations of time, linearity of progress, or even outcomes. For example, recommended rates for healthy weight loss is one to two pounds per week [171], so clients should expect to lose 10 lbs. no sooner than in 5–10 weeks, or longer. They should not expect day-to-day measurements such as body weight to show linear progress, nor should they expect to look like a model in a magazine after the weight is lost. Outcomes related to lifestyle changes require long-term adherence and consistency, and progress is influenced by a variety of factors including sleep, stress, nutrition, training intensity and frequency, genetics, etc.

To combat frustration and develop an internal locus of control [172], professionals should place a greater emphasis on habits and behaviors rather than outcomes as markers of success and progress. In obese patients, simple habits-based weight loss interventions have produced clinically significant weight loss outcomes [173]. Further, 12 months following habits-based interventions in overweight or obese participants, participants have been shown to not only maintain but also exceed post-intervention weight loss outcomes [174]. Managing expectations, and shifting focus to health habits rather than outcomes, can improve long-term adherence to lifestyle interventions.

Providing and Encouraging Social Support

One of the ways professionals can help clients adhere to nutrition and exercise changes is through social support. In addition to supporting them personally, this may include helping new clients make connections within the facility, or encouraging involvement of partners, family members, or friends in physical activity/nutrition changes. The attitudes and actions of loved ones strongly influence health behavior [175], so familial involvement can be particularly effective. However, in general, strong social networks are associated with health-promoting behaviors [176], and those with social support have been shown to be 61% more likely to engage in behavior changes [177]. Further, social support can improve delay of gratification behaviors [178], which is often required to engage in health behaviors, such as nutrition and exercise.

Summary

Self-management is a well-established strategy for disease management; however, these same strategies can be utilized by nutrition and exercise professionals to improve client adherence and promote disease prevention. Increasing awareness of the health risks surrounding excess body fat and sedentary behaviors, in conjunction with the growth in the diet and fitness industries, presents an exceptional opportunity for health and fitness professionals to play a critical role in public health. Through habits-based and autonomy-promoting coaching, such as that in self-management, cultural and personal barriers to nutrition and exercise can be addressed, and professionals will be able to facilitate sustainable health behaviors.

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