

# Chapter 14

## Self-management

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### **Key Points**

- The WHO defines chronic disease as a long-lasting condition, with a fluctuating course, that can be controlled but not cured.
- Human immunodeficiency virus (HIV) can be considered a chronic disease that may benefit from self-management programs.
- Self-rated successful aging in adults with HIV is related to better physical and mental health functioning, increased happiness, greater resilience, optimism, personal mastery, better attitudes toward aging, fewer depressive symptoms, and less perceived stress.
- Empowerment of the patient requires changing the roles in the traditional medical system. Promoting

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patient empowerment and self-management includes addressing complex issues, such as medication adherence and prevention of transmission.

- Clinicians can help improve patient well-being by focusing on interventions that enhance positive psychological traits.

The WHO defines a chronic disease as a prolonged condition, with a fluctuating course, that is rarely cured completely [1–3]. Thus, chronic disease management also aims to control the disease symptoms and prevent functional impairment [4] through interventions that include managing physical symptoms, improving independence, and increasing quality of life [5, 6]. Patients dealing with multiple chronic conditions face multiple challenges in managing their health, including poor coordination of medical care, managing multiple medications (polypharmacy), and increased risk of aggravating one condition by symptoms or treatment of another.

When thinking and planning for living well with increasing age, the patient needs to recognize and accept these changes and adapt their lifestyle to this new stage. This leads to a shift from the ‘traditional’ disease treatment paradigm to patients assuming an active and informed role in managing the multi-varied physical, psychological, and social aspects of health.

Self-management is considered by the WHO as the best practice to improve clinical care and outcomes for chronic conditions [7]. Patient empowerment means changing the roles in the traditional medical system [8]. In this setting, patients are responsible for talking their medications properly, changing their behavior to improve symptoms or slow disease progression, interpreting and reporting symptoms correctly, adjusting to new social and economic circumstances, coping with emotional consequences, participating in treatment decisions, and preventing transmission of contagious diseases [9].

Several studies have shown that self-management programs are associated with reduced morbidity, lower number of visits to acute medical services, and improvement in organ

TABLE 14.1 The JUSTRI Wellness Checklist [12]

**Wellness Checklist**Daily

1. Could I exercise more today?
2. Have I bought the right food?
3. Should I drink less alcohol today?
4. Am I doing the right things to help me sleep properly?
5. Am I doing something new today?
6. Am I keeping my brain active?

Weekly

1. Am I doing something nice with a friend this week?
2. What is my weight and is it changing?
3. Have I planned an active weekend?
4. Am I eating healthily?

Every 3–4 months

1. Do I feel well or unwell?
2. Have I had my check up at the clinic?
3. What are my blood results?
4. Have I stopped smoking?
5. Are my finances in order?
6. How has my mood been recently?
7. What are my plans for the next few months?

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function and quality of life [10, 11]. Consequently, these programs not only improve patient outcomes, but also reduce the burden on health care system resources and capacities.

An interesting example of patient empowerment is the Wellness Checklist (Table 14.1), suggested by JUSTRI (a not-for-profit

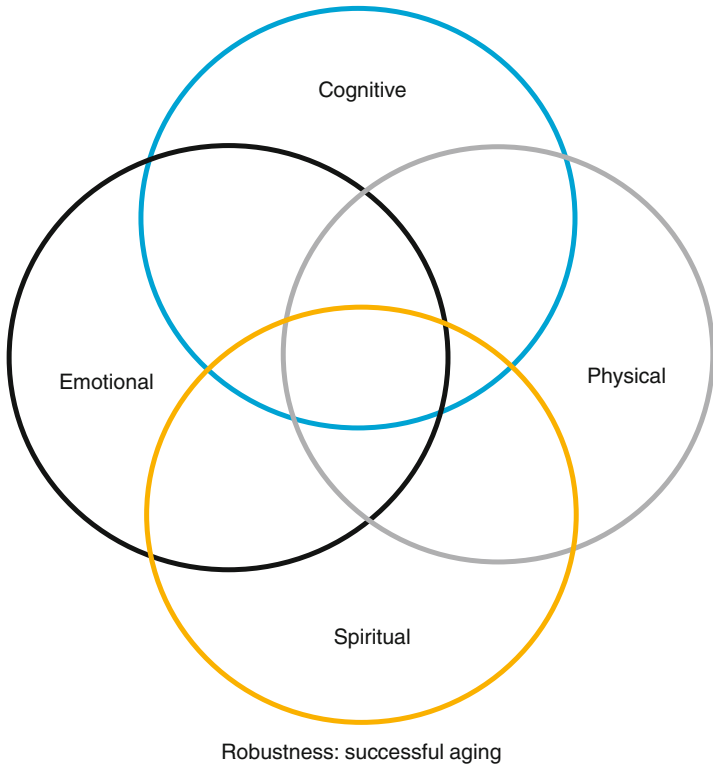
organization established to work with allies in the health care and patient communities), as a periodical self-assessment to increase awareness of aging and promote successful aging.

HIV has been recognized as a chronic illness since the advent of antiretroviral therapy (ART) [13–16], but it is still not universally included in chronic illness lists and discussions [3, 17, 18].

For the older patient with HIV, a recognized potential barrier to effective disease management is the increased complexity in managing ART regimens, as well as the often numerous medications necessary for concurrent chronic conditions. Successful aging in this population is a therefore complex and dynamic concept (Fig. 14.1).

Baltes and Baltes [19] used eight factors in defining successful aging: length of life, biological health, cognitive efficiency, mental health, social competence, productivity, personal control, and life satisfaction. Vance et al. [20] explored how HIV, medication side effects, and lifestyle choices interfere with these pathways to successful aging (Fig. 14.2).

Successful cognitive aging (SCA) involves a dynamic interaction between numerous factors, and has been defined as aging without subjective or objective cognitive impairment, depressive symptoms, or functional impairment [21, 22]. Among people aging with HIV, SCA is associated with better mental quality of life [21], medication adherence, and capacity to interact with health professionals [22]. Cognitive decline (which may be inevitable in the aging population) is associated negatively with SCA. Decline in cognitive function is partially related to poor medication adherence [23]. This can lead to antiretroviral (ARV) resistance and result in poor physical health, which in turn can lead to decreased survival. Poor medication adherence can also lead to a lapse in HIV control, with compromised control of central nervous system HIV effects resulting in further cognitive decline. Worsening of cognitive efficiency can also result in decreased social competence, productivity, and mental health (which interact to further exacerbate these declines). As a consequence, people living with HIV (PLWH) feel powerless and live with uncertainty [24]. The feeling of powerlessness further contributes to ill health [25].



**FIGURE 14.1** The multiple interactions of life domains associated with successful aging

Promoting patient empowerment and self-management for PLWH includes addressing complex issues, such as medication adherence and prevention of HIV transmission.

One of the major differences between HIV and other chronic diseases is not medical, but related to sociocultural factors. Challenges in the HIV-positive population include coping with stigma, shame, discrimination, social rejection, and strategically managing disclosure [26]. There is an increased complexity of self-management, with the need to address individual, family, and health care system factors [27].

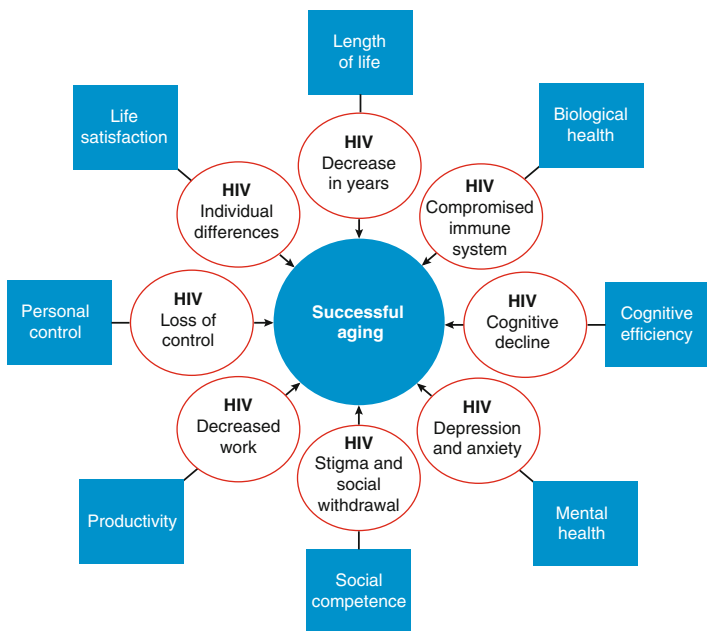


FIGURE 14.2 Factors of and obstacles to successful aging with HIV (Adapted from Vance et al. [20])

Numerous intervention studies have demonstrated success in changing health-related behaviors of PLWH, including:

- improving adherence to medication regimens [28];
- reducing risk of transmission [29, 30];
- increasing self-care (ie, nutrition, exercise, sleep);
- emotional regulation [31];
- social support [31];
- reducing substance use [32];
- improving quality of life [33];
- reducing social stigma [34]; and
- increasing immune system functioning [35].

There are several standardized assessments, which include questions about self-management knowledge, skills,

confidence, supports, and barriers [36–38], enabling the health care team to further support patient self-management efforts. These assessments should be tailored to include the diverse personal and cultural contexts [39–43] across different health care settings. Non-invasive, non-medical cognitive interventions are favored, especially since they are inexpensive and do not place medication demands on a clinical population for which there is already a heavy pharmaceutical burden [44, 45].

Recognizing HIV as a chronic disease has implications for medical care and delivery, public policy, and the well-being of PLWH. This is particularly important in low-resource settings with limited health care workforce, supplies, and facilities, where an integrative self-management framework allows PLWH to receive care without putting an additional strain on resources. However, at present there remains a significant gap in translating proven chronic disease research findings and interventions into practice. Better dissemination and implementation of evidence-based interventions is critical to truly benefit children, families, adults, and communities facing disease management challenges [46].

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