

Published in final edited form as:

AIDS Care. 2009 October; 21(10): 1321-1334. doi:10.1080/09540120902803158.

Common elements in self-management of HIV and other chronic illnesses: an integrative framework

Dallas Swendeman^{a,*}, Barbara L. Ingram^b, and Mary Jane Rotheram-Borus^a

- ^a Global Center for Children and Families, Semel Institute for Neuroscience and Human Behavior, University of California, Los Angeles, CA, USA
- ^b Graduate School of Education and Psychology, Pepperdine University, Los Angeles, CA, USA

Abstract

HIV/AIDS is widely recognized as a chronic illness within HIV care, but is often excluded from chronic disease lists outside the field. Similar to other chronic diseases, HIV requires lifetime changes in physical health, psychological functioning, social relations, and adoption of disease-specific regimens. The shift from acute to chronic illness requires a self-management model in which patients assume an active and informed role in healthcare decision making to change behaviors and social relations to optimize health and proactively address predictable challenges of chronic diseases generally and HIV specifically. This article reviews literature on chronic disease self-management to identify factors common across chronic diseases, highlight HIV-specific challenges, and review recent developments in self-management interventions for people living with HIV (PLH) and other chronic diseases. An integrated framework of common elements or tasks in chronic disease selfmanagement is presented that outlines 14 elements in three broad categories: physical health; psychological functioning; and social relationships. Common elements for physical health include: a framework for understanding illness and wellness; health promoting behaviors; treatment adherence; self-monitoring of physical status; accessing appropriate treatment and services; and preventing transmission. Elements related to psychological functioning include: self-efficacy and empowerment; cognitive skills; reducing negative emotional states; and managing identity shifts. Social relationship elements include: collaborative relationships with healthcare providers; social support; disclosure and stigma management; and positive social and family relationships. There is a global need to scale up chronic disease self-management services, including for HIV, but there are significant challenges related to healthcare system and provider capacities, and stigma is a significant barrier to HIV-identified service utilization. Recognizing that self-management of HIV has more in common with all chronic diseases than differences suggests that the design and delivery of HIV support services can be incorporated into combined or integrated prevention and wellness services.

Keywords

| AIDS; HI | V; chronic | illness; | chronic c | care model | common | elements; | self-managei | nent |
|----------|------------|----------|-----------|------------|--------|-----------|--------------|------|
| | | | | | | | | |

Publisher's Disclaimer: Full terms and conditions of use: http://www.informaworld.com/terms-and-conditions-of-access.pdf This article may be used for research, teaching and private study purposes. Any substantial or systematic reproduction, re-distribution, re-selling, loan or sub-licensing, systematic supply or distribution in any form to anyone is expressly forbidden. The publisher does not give any warranty express or implied or make any representation that the contents will be complete or accurate or up to date. The accuracy of any instructions, formulae and drug doses should be independently verified with primary sources. The publisher shall not be liable for any loss, actions, claims, proceedings, demand or costs or damages whatsoever or howsoever caused arising directly or indirectly in connection with or arising out of the use of this material.

Corresponding author. dswendeman@mednet.ucla.edu.

Introduction

When effective treatment of incurable diseases extends life expectancy and causes symptom remission, acute and terminal illness models must be replaced by a chronic care model (CCM) in which patient self-management is a key component (Bodenheimer, Lorig, Holman, & Grumbach, 2002). HIV has been recognized as a chronic illness since the advent of anti-retroviral therapy (ART; Beaudin & Chambré, 1996; Ho, 1998; Mitchell & Linsk, 2004; Schmitt & Stuckey, 2004), but HIV is still not universally included in chronic illness lists and discussions (e.g., Marks, Allegrante, & Lorig, 2005; National Center for Chronic Disease Prevention and Health Promotion, 2008; World Health Organization, 2008).

In countries where ART is widely available, there has been steady improvement in life expectancy and lowered mortality rate for people living with HIV (PLH). For example, in the UK, mortality rates among PLH dropped from 4.7% in 1997 to 0.9% in 2007 (National AIDS Trust, 2009). In Denmark, estimated median survival for young PLH is 35+ years (Lohse et al., 2007). Average life expectancy following discovery of seropositive status in the US is almost two decades (Schackman et al., 2006), mortality has decreased approximately 70% since 1995, and AIDS has fallen from the first to the fifth leading cause of death for people ages 25–44 (Center of Excellence on Health Disparities, 2009). Globally, the number of PLH has increased partly due to more widely available ART, making chronic disease management programs and adherence a global priority (UNAIDS, 2008).

Aberg (2006) summarized studies showing that not only does HIV meet criteria for chronic illness when medication is available, but the increased lifespan of PLH means that they will likely develop similar chronic diseases to non-PLH populations. A study of causes of death of PLH in New York City (1999–2004) found the three leading causes of death from non-HIV-related causes were substance abuse, cardiovascular disease, and cancer, leading to the recommendation that the HIV healthcare model shift from a primary focus on managing HIV infection "to providing care that addresses all aspects of physical and mental health" (Sackoff, Hanna, Pfeiffer, & Torian, 2006).

Political will and funding commitments are now in place to support global scale-up of HIV treatment, care, and prevention (Chan, 2007), which are now recognized as being inextricably linked rather than competing for resources (Horton & Das, 2008). Yet, healthcare system and provider capacities are not in place to meet global healthcare needs and disease-specific programs and funding often distort local healthcare capacities and priorities (England, 2007). For HIV-specific programs, stigma is a significant barrier to service delivery and utilization (Mahajan et al., 2008). Thus, integrative programs, rather than disease-specific programs, are being recommended to strengthen healthcare systems by bridging funding and capacities across diseases (Merson, O'Malley, Serwadda, & Apisuk, 2008; Ooms, Van Damme, Baker, Zeitz, & Schrecker, 2008). This paper presents an integrative framework that outlines the common elements of chronic illness self-management across diseases and highlights HIV-specific challenges. The goal is to support providers, planners, researchers, and PLH to design and deliver care and support services in both disease-specific and integrated programs.

Chronic disease care and self-management

Chronic diseases are prolonged, have a fluctuating course, and are rarely cured completely (McDonald, 2003; UK Department of Health, 2004; World Health Organization, 2008). HIV meets several chronic disease criteria: uncertain course, a prescribed treatment regimen, requirement for self-care, some degree of stigma, changes in roles and relationships, identity changes, and psychological distress (Siegel & Lekas, 2002). The goal of chronic illnesses healthcare is to control symptoms and prevent disability rather than cure the disease (Creer, Holroyd, Glasgow, & Smith, 2004). Thus, the objectives of chronic disease interventions

include managing physical symptoms, improving independence, and increasing quality of life (Kennedy, Hopwood, & Duff, 2001; Willison & Andrews, 2003).

With chronic illness, in contrast to acute illness, the patient is the principal caregiver (Holman & Lorig, 1997). The majority of illness management takes place outside of formal healthcare (Gately, Rogers, & Sanders, 2007) with patients engaged in day-to-day "illness work" (Corbin & Strauss, 1995). Patients are responsible for: using medication properly, changing 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 (Holman & Lorig, 1997). Thus, the shift from acute to chronic care brings emphasis to self-management of disease, where patients assume an active and informed role in managing physical, psychological, and social aspects of health.

The WHO includes self-management as a best practice to improve clinical care and outcomes for chronic conditions (World Health Organization, 2001). Programs that educate and support patients to manage their own conditions have demonstrated success in achieving improved health outcomes (Epping-Jordan, Bengoa, Kawar, & Sabaté, 2001). For example, asthma self-management programs are effective in reducing morbidity, lessening requirements for acute medical services, and improving lung function and quality of life (Fishwick, D'Souza, & Beasley, 1997). Similarly, hospital visits are reduced when self-management training is provided to people with chronic obstructive pulmonary disease (COPD; Bourbeau, Nault, & Dang-Tan, 2004). Thus, self-management programs not only improve patient outcomes, but also reduce burden on healthcare system resources and capacities.

Method

The literature on chronic illness self-management was searched on Medline, PsycInfo, Science Direct, and Web of Science using "chronic illness," "chronic disease," and "self-management" combined with specific chronic diseases (e.g., arthritis, asthma, diabetes, COPD, HIV/AIDS, etc.). Article reference lists and the websites of government health departments, the WHO, and disease-specific organizations were also searched. Selected articles synthesized the literature on self-management, described program implementation, or addressed health policy issues regarding self-management programs. The search was limited to English articles and excluded dissertations. Authors reviewed each abstract to eliminate articles that were not relevant.

Selected articles were reviewed to identify elements of chronic disease self-management interventions that were either explicitly stated (e.g., "learn to monitor blood glucose levels" or "increase self-efficacy beliefs") or implied in intervention descriptions (e.g., "increase social support" and "promote patient empowerment"). Common and HIV-specific program elements were classified and categorized into three broad domains (physical health, psychological functioning, and social relationships).

Results

Goals for chronic disease self-management programs

A comprehensive literature review identified similar behavior change goals for all chronic diseases, including adoption of a healthy lifestyle (e.g., sufficient sleep, moderation in use of alcohol, good nutrition, weight control, smoking cessation, exercise, and regular health care); adherence to treatment protocols, particularly medication; stress, anger, and depression management; and effective communication with health professionals (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Creer et al., 2004; Lorig et al., 2001; Smith & Ruiz, 2002; Wright, Barlow, Turner, & Bancroft, 2003). Examples for specific diseases include

improved eating and increased physical activity for Type II diabetes (Clark & Hampson, 2001; Skinner et al., 2006); increased use of exercise and relaxation for arthritis (Lorig et al., 1999); proper medication use, weight control, healthy food choices, smoking cessation, and physical exercise for vascular diseases (Sol, van der Bijl, Banga, & Visseren, 2005); and healthy sleep patterns, avoiding alcohol, and obtaining social support for epilepsy (Kobau & DiIorio, 2003).

Collaboration in care and decision making

Management of chronic disease requires that patients not only comply with physicians' instructions but also assume an active role in decision making, problem solving, and implementation of a personalized treatment plan to become "informed, activated patients in partnership with their physicians" (Bodenheimer, Wagner, & Grumbach, 2002). Patients practicing self-management must share responsibility for setting goals and creating action plans (Creer et al., 2004; Schreurs, Colland, Kuijer, de Ridder, & van Elderen, 2003), to overcome limitations of traditional programs that teach patients self-monitoring skills without decision-making responsibility (Bodenheimer et al., 2002a). Programs with patient decision making and action planning are associated with better outcomes because patients are able to make treatment changes based on their recognition of changes in disease severity and in accordance with predetermined guidelines (Fishwick et al., 1997).

HIV-specific programs

Successful self-management models with HIV also emphasize the development of behavioral skills (Gifford & Groessl, 2002; Inouye, Flannelly, & Flannelly, 2001; Kennedy, Rogers, & Crossley, 2007b; Miles et al., 2003). Kelly and Kalichman (2002) describe the major HIV-specific challenges as adhering to complex medication regimens, coping with successes and setbacks, and living with uncertainty. Numerous intervention studies have demonstrated success in changing health-related behaviors of PLH, including improving adherence to medication regimens (Gordon, 2006); reducing risk of transmission (Albarracín et al., 2005; Crepaz & Marks, 2003); increasing self-care (i.e., nutrition, exercise, sleep), emotional regulation, and social support (Rotheram-Borus et al., 2001a); reducing substance use (Rotheram-Borus et al., 2004); improving quality of life (Rotheram-Borus et al., 2001b) reducing social stigma (Holzemeyer & Urs, 2004) and increasing immune system functioning (Antoni et al., 2005).

The Positive Self-Management Program (PSMP; http://www.livingwelluk.com/psmp.htm; Gifford & Sengupta, 1999; Kennedy et al., 2007b) combines health education with self-management skills, assuring that patients understand risks and benefits of treatment options in order to actively participate in medical decisions. Research on Cognitive Behavioral Therapy (CBT) techniques (Biswas, 2007; Crepaz et al., 2008) and stress management interventions (Scott-Sheldon, Kalichman, Carey, & Fielder, 2008) focused on self-management, and demonstrated positive effects on stress, emotional symptoms, and quality of life. A peer-led self-management program in San Francisco reduced symptom severity and increased stress-management behaviors (Gifford, Laurent, Gonzales, Chesney, & Lorig, 1998). Henry, Holzemer, Weaver, and Stotts (1999) used self-management techniques successfully with PLH to reduce chronic diarrhea. Smith, Rublein, Marcus, Brock, and Chesney (2003) found empirical support for the benefit of a self-management program for adherence to ART regimens.

Integrated programs

Recognition that the same self-management skills are needed for all chronic illnesses has led to the development of integrated intervention programs for various chronic diseases. The Chronic Disease Self-Management Program (Lorig et al., 1999) and UK Department of Health

"Expert Patients Programme" (Donaldson, 2003) address universal self-management tasks for groups with mixed chronic illness diagnoses. Integrated programs demonstrate success in enhancing self-management of exercise, pain, depression, nutrition, communication, goal setting, and behavioral contracting, and have been used effectively in many countries including the UK (Bray, 2004; Gately et al., 2007; Kennedy et al., 2007a), Australia (Swerissen et al., 2006), and China (Fu, Ding, McGowan, & Fu, 2006). In Cambodia, Janssens et al. (2007) found that including PLH in a program with diabetes and hypertension patients reduces stigma for PLH and facilitates efficient use of health care resources.

Published descriptions of chronic illness self-management interventions demonstrate that they share common intervention elements, which can be broadly categorized as action steps with providers and targeted self-management outcomes. Table 1 shows intervention elements described in three specific programs and two review articles, separated as action steps and outcomes. Although the published descriptions varied in the number of elements outlined and their level of detail or specificity, they all reflect the same common elements. Action steps with providers broadly reflect the steps taken in provider-patient interactions to teach cognitive skills of self-management, which are focused on goal setting, problem solving, decision making, and self-monitoring of progress on goals. Targeted outcomes reflect the goals emphasized in the intervention descriptions, and while they also vary in emphasis and detail, they do all reflect broad and common goals of self-management interventions to support physical health (e.g., medication adherence, symptom management, and healthy lifestyle routines), psychological functioning (e.g., managing stress, promoting self-esteem, and maintaining positive emotional states), and social relationships (e.g., collaborative providerpatient interactions, accessing social support, and enhancing role, and relationship functioning). Table 2 synthesizes the goals of chronic disease self-management interventions into 14 elements categorized in physical, psychological, and social domains. For each disease, in addition to common elements, there will be disease-specific needs: for instance, diabetics need to learn specific skills to manage glucose levels and care for feet (Skinner et al., 2006). Table 2 summarizes the common elements for self-management and HIV-specific needs.

Discussion

Challenges in self-management programs

Qualitative studies demonstrate the diverse needs of PLH and the complexity of self-management that addresses individual, family, and healthcare system factors (Chou & Holzemer, 2004). For example, many PSMP participants' needs and expectations were not met because of over-emphasis on self-efficacy in the program (Kennedy et al., 2007b). Sanders, Rogers, Gately, and Kennedy (2008) suggested that mandatory inclusion of advance care planning in the Expert Patients Program had a negative effect by bringing topics of death and dying into a program focused on positive self-management strategies. Thorne, Paterson, Russell, and Schultz (2002) found that complementary and alternative medicine (CAM) use among PLH is not a rejection of conventional medicine but rather a component of responsible self-care management. Studies of PLH across cultures demonstrate diversity of needs and the importance of tailoring interventions to personal and cultural contexts (Kemppainen et al., 2006; Nicca, Moody, Elzi, & Spirig, 2007; Sankar & Luborsky, 2003; Tsai, Hsiung, & Holzemer, 2002). For instance, Miller (2008) describes implementation of the "Living Well Programme" from London in several African countries, and the need to be aware of cultural differences, including the novelty of the concept of "responsibility" for African women.

HIV-specific challenges

Promoting self-management for PLH includes addressing complex issues such as medication adherence and prevention of transmission. While these issues must be recognized specifically

for PLH, they are not unique to HIV. The complexity of adherence to ART regimens and their costs are recognized as potential barriers to effective management of HIV, which are similar to the complicated self-administered treatments for other chronic and co-morbid conditions.

Thus compared to other chronic diseases, three factors stand out as being particularly challenging for self-management of HIV, lack of direct self-monitoring of physical status, stigma and disclosure, and criminalization of HIV exposure. Similarly, the fact that HIV is sexually transmitted highlights the importance of behavior change for PLH, but does not make HIV unique, as other incurable infectious diseases must also be managed as chronic conditions, such as herpes and hepatitis C.

Lack of direct self-monitoring of physical status

While patients' ability to monitor health status varies by chronic illness, it is an important and common element of chronic disease self-management. PLH can monitor their physical functioning and receive feedback about their viral load and CD4 cell count through laboratory test results but there is currently no direct method for physiological self-monitoring of HIV disease progression. The link between stress and immune function (Boyce et al., 1995; Uchino, Cacioppo, & Kiecolt-Glaser, 1996) suggests that technologies for self-monitoring of stress biomarkers (e.g., cortisol level, Epstein-Barr antibodies, and proteins that mediate inflammatory responses) may provide a means to self-monitor immune function. Measures of psychological and physiological stress such as allostatic load, physiological effects on body systems, and cortisol levels in the saliva, have been found to be related to vulnerability to infections (Cohen, Frank, Doyle, Skoner, & Rabin, 1998; Glaser, Kiecolt-Glaser, Malarkey, & Sheridan, 1998; Glaser, Rabin, Chesney, Cohen, & Natelson, 1999; Worthman & Panter-Brick, 2008), which is an important biomarker for immuno-compromised PLH. If technology for patient self-monitoring of viral load and CD4 cell count became available, there are risks that information about fluctuations in viral load might increase psychological distress and diminish feelings of control among PLH, unless the data gathered can inform treatment modification, as with diabetes.

HIV/AIDS stigma

One major difference between HIV and other chronic diseases is not medical, but based on sociocultural factors such as homophobia and the faulty assumption that most AIDS patients contracted the disease from immoral behavior. Predictable challenges for PLH include coping with stigma, shame, discrimination, social rejection, and strategically managing disclosure (Herek, 1999). The degree to which people blame PLH for their illness varies by context. In Britain, between 48 and 64% believe that people who contract HIV through unprotected sex or drug use have themselves to blame (Jack, 2008). Research in the USA demonstrates that disclosure of HIV status brings greater negative consequences than disclosure of other diseases (Kiecolt-Glaser et al., 2007; Lee & Rotheram-Borus, 2002; Lee, Rotheram-Borus, & O'Hara, 1999; Murphy, Greenwell, Resell, Brecht, & Schuster, 2008). AUS survey asking people about prejudice toward people with HIV/AIDS shows that discrimination is diminishing (Pew Global Attitudes Project, 2007). Disclosure of one's disease status to others and coping with social rejection are experiences that add stressors to the burden of living with an incurable infectious disease. Although HIV/AIDS stigma may be high, stigma is also experienced by people with epilepsy (Baruchin, 2007; Fernandes et al., 2007), diseases of the colon because of risk of embrassing oders (de Rooy et al., 2001), and obesity (Bray, 2004).

Criminalization of HIV exposure

Perhaps the most distinctive aspect of HIV is laws that criminalize behavior by a PLH, aware of seropositive status, that puts another person at risk for contracting HIV. As of 2005, 24 states in the USA have laws that make HIV exposure a felony and four states a misdemeanor; in most

cases the victim need not be infected for prosecution of PLH and penalties range from a minimum of one year to a maximum of life in prison (Center for AIDS Prevention Studies, 2005; Kaiser Family Foundation, 2005). The Global Network of People Living with HIV/AIDS in Europe surveyed European countries and found that the majority have similar criminalization laws (http://www.gnpplus.net/criminalisation/rapidscan.pdf). Critiques of these laws suggest that they undermine prevention efforts by increasing reluctance for people to get tested for HIV do not reduce HIV transmission, and detract from the structural drivers of HIV infection.

Conclusions

Recognition of HIV as a chronic disease has implications for medical care and delivery, public policy, and the well-being of PLH. PLH share many of the same experiences as patients with other chronic illnesses and can benefit from the same health care models and programs, including self-management. In low-resource settings with limited healthcare workforce, supplies, and facilities, an integrative self-management framework allows PLH to receive care without putting an additional strain on resources through HIV-specific programs, with reduced stigma. There is evidence that chronic disease management is already receiving increased focus in primary care in other countries (e.g., Shanghai; Fu et al., 2003). Miller (2008) has successfully applied self-management programs in African countries, demonstrating the potential this model brings to underserved populations.

Chronic disease management for HIV enables PLH to proactively address predictable challenges and sustain long term changes in everyday behavioral routines. Wide dissemination of the self-management model will require changes in healthcare systems and professional roles, with non-physician personnel having increased responsibility in chronic care management (Bodenheimer et al., 2002a). Advantages of self-management include peer support and education that can become the cornerstone of programs for maintaining health, and promoting sustainability, cultural sensitivity, and replicability. When HIV is framed as a chronic condition, PLH can receive the same general care as people with other chronic diseases and identify with a larger population of people diagnosed with chronic diseases. Rather than isolating PLH with a condition traditionally associated with stigma and discrimination, chronic disease management of HIV will facilitate the continued mainstreaming of PLH, reduce stigma, and expand healthcare resources for all.

References

- Aberg JA. The changing face of HIV care: Common things really are common. Annals of Internal Medicine 2006;145(6):463–465. [PubMed: 16983135]
- Albarracín D, Gillette JC, Allison N, Glasman LR, Durantini MR, Ho MH. A test of major assumptions about behavior change: A comprehensive look at the effects of passive and active HIV-prevention interventions since the beginning of the epidemic. Psychological Bulletin 2005;131:856–897. [PubMed: 16351327]
- American Society for Microbiology. Report suggests infectious connection to chronic diseases. Science Daily. 2005 Apr 22. Retrieved February 5, 2008, from http://www.sciencedaily.com/releases/2005/04/050422165507.htm
- Anderson RM. Patient empowerment and the traditional medical model: A case of irreconcilable differences? Diabetes Care 1995;18:412–415. [PubMed: 7555490]
- Antoni MH, Cruess DG, Klimas N, Carrico AW, Maher K, Cruess S, et al. Increases in a marker of immune system reconstitution are predated by decreases in 24-hour urinary cortisol output and depressed mood during a 10-week stress management intervention in symptomatic HIV-infected men. Journal of Psychosomatic Research 2005;58:3–13. [PubMed: 15771864]
- Aujoulat I, d'Hoore W, Deccache A. Patient empowerment in theory and practice: Polysemy or cacophony? Patient Education and Counseling 2007;66(1):13–20. [PubMed: 17084059]

Australian Institute of Health and Welfare. Chronic diseases and associated risk factors. 2008. Retrieved January 22, 2008, from http://www.aihw.gov.au/cdarf/index.cfm

- Barlow J, Wright C, Sheasby J, Turner A, Hainswroth J. Self-management approaches for people with chronic conditions: a review. Patient Education and Counseling 2002;48(2):177–187. [PubMed: 12401421]
- Baruchin, A. Battling epilepsy, and its stigma. New York Times. 2007 Feb 20. Retrieved October 23, 2007, from http://www.nytimes.com/2007/02/20/health/20epil.html?_r-1&oref-slogin
- Baumgartner LM. The incorporation of the HIV/AIDS identity into the self over time. Qualitative Health Research 2007;17(7):919–931. [PubMed: 17724104]
- Beaudin CL, Chambré SM. HIV/AIDS as a chronic disease: Emergence from the plague model. American Behavioral Scientist 1996;39:684–706.
- Bellg AJ. Maintenance of health behavior change in preventive cardiology. Internalization and self-regulation of new behaviors. Behavioral Modification 2003;27(1):103–131.
- Biswas UN. Promoting health and well-being in lives of people living with HIV and AIDS. Psychology and Developing Societies 2007;19(2):215–247.
- Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. Journal of the American Medical Association 2002a;288(14):1775–1779. [PubMed: 12365965]
- Bodenheimer T, Lorig L, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. Journal of the American Medical Association 2002b;288(19):2469–75. [PubMed: 12435261]
- Bourbeau J, Nault D, Dang-Tan T. Self-management and behaviour modification in COPD. Patient Education and Counseling 2004;52(3):271–277. [PubMed: 14998597]
- Boyce WT, Chesney M, Alkon A, Tschann J, Adams S, Chesterman B, et al. Psychobiologic reactivity to stress and childhood respiratory illnesses: Results of two prospective studies. Psychosomatic Medicine 1995;57:411–422. [PubMed: 8552730]
- Bray GA. Medical consequences of obesity. Journal of Clinical Endocrinology and Metabolism 2004;89 (6):2583–2589. [PubMed: 15181027]
- Burns S, Cameran E. The Case Against Criminalization of HIV Transmission. Journal of the American Medical Association 2008;300(5):578–581. [PubMed: 18677032]
- Center for AIDS Prevention Studies University of California San Francisco (CAPS). Is there a role for criminal law in HIV prevention? Fact Sheet #57E. 2005. Retrieved January 22, 2008, from http://www.caps.ucsf.edu/pubs/FS/criminalization.php
- Center of Excellence on Health Disparities. HIV/AIDS Core: Fact Sheet. 2009. Retrieved February 26, 2009, from http://web.msm.edu/EXPORT/HIV_fact.htm
- Chan, M. Fostering new models of science development and collaboration: Address to the eleventh global forum for health research. Evidence and policy in the globalized response to AIDS. In: Oelrichs, R.; Boyd, M., editors. Current Opinion in HIV/AIDS. Vol. 3. 2007. p. 477-480.
- Charmaz, K. Good days, bad days: The self in chronic illness and time. New Brunswick, NJ: Rutgers University Press; 1991.
- Chenard C. The impact of stigma on the self-care behaviors of HIV-positive gay men striving for normalcy. Journal of the Association of Nurses in AIDS Care 2007;18(3):23–32. [PubMed: 17570297]
- Chou FY, Holzemer WL. Linking HIV/AIDS clients' self-care with outcomes. Journal of the Association of Nurses in AIDS Care 2004;15(4):58–67. [PubMed: 15296659]
- Clark M, Hampson SE. Implementing a psychological intervention to improve lifestyle self-management in patients with type 2 diabetes. Patient Education and Counseling 2001;42:247–256. [PubMed: 11164324]
- Cohen S, Frank E, Doyle WJ, Skoner DP, Rabin BS. Types of stressors that increase susceptibility to the common cold in healthy adults. Health Psychology 1998;17:214–223. [PubMed: 9619470]
- Corbin J, Strauss A. Managing chronic illness at home: Three lines of work. Qualitative Sociology 1995;8 (3):224–247.
- Creer, TL.; Holroyd, KA.; Glasgow, RE.; Smith, TW. Health psychology. In: Lambert, MJ., editor. Bergin and Garfield's handbook of psychotherapy and behavior change. 5. New York, NY: John Wiley & Sons; 2004. p. 697-742.

Crepaz N, Marks G. Serostatus disclosure, sexual communication and safer sex in HIV-positive men. AIDS Care 2003;15:379–387. [PubMed: 12745398]

- Crepaz N, Passin WF, Herbst JH, Rama SM, Malow RM, Purcell DW, et al. Meta-analysis of cognitive-behavioral interventions on HIV-positive persons' mental health and immune functioning. Health Psychology 2008;27(1):4–14. [PubMed: 18230008]
- deRooy EC, Toner BB, Mauder MD, Greenberg GR, Baron D, Steinhart AH, et al. Concerns of patients with inflammatory bowel disease: From a clinical population. American Journal of Gastroenterology 2001;96(6):1822–1830. [PubMed: 11419836]
- Donaldson L. Expert patients usher in a new era of opportunity for the NHS. British Medical Journal 2003;326:1279–1280. [PubMed: 12805129]
- England R. The dangers of disease-specific programmes for developing countries. British Medical Journal 2007;335(7619):565.
- Epping-Jordan J, Bengoa R, Kawar R, Sabaté E. The challenge of chronic conditions: WHO responds. British Medical Journal 2001;323:947–948. [PubMed: 11679371]
- Fernandes PT, Salgado PCB, Noronha ALA, de-Boer HM, Prilipko L, Sander JR, et al. Epilepsy stigma perception in an urban area of a limited-resource country. Epilepsy Behavior 2007;11:25–32. [PubMed: 17613276]
- Fishwick D, D'Souza W, Beasley R. The asthma self-management plan system of care: What does it mean, how is it done, does it work, what models are available, what do patients want and who needs it? Patient Education and Counseling 1997;32:S21–S33. [PubMed: 9516757]
- Fu D, Ding Y, McGowan P, Fu H. Qualitative evaluation of chronic disease self management program (CDSMP) in Shanghai. Patient Education and Counseling 2006;61:389–396. [PubMed: 15975756]
- Fu D, Fu H, McGowan P, Shen YE, Zhu L, Yang H, et al. Implementation and quantitative evaluation of chronic disease self-management programme in Shanghai, China: Randomized controlled trial. Bulletin of the World Health Organization 2003;81(3):174–182. [PubMed: 12764513]
- Gately C, Rogers A, Sanders C. Re-thinking the relationship between long-term condition self-management education and the utilization of health services. Social Sciences and Medicine 2007;65:934–945.
- Gifford AL, Groessl EJ. Chronic disease self management and adherence to HIV medication. Journal of acquired Immune Deficiency Syndrome 2002;15(Suppl 3):S163–S166.
- Gifford AL, Laurent DD, Gonzales VM, Chesney MA, Lorig KR. Pilot randomized controlled trial of education to improve self-management skills of men with symptomatic HIV/AIDS. Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology 1998;18:136–144. [PubMed: 9637578]
- Gifford AL, Sengupta S. Self-management health education for chronic HIV infection. AIDS Care 1999;11(1):115–130. [PubMed: 10434987]
- Glaser R, Kiecolt-Glaser JK, Malarkey WB, Sheridan JF. The influence of psychological stress on the immune response to vaccines. Annals of the New York Academy of Sciences 1998;840:649–855. [PubMed: 9629291]
- Glaser R, Rabin B, Chesney M, Cohen S, Natelson B. Stress-induced immunomodulation: Implications for infectious diseases? Journal of the American Medical Association 1999;281:2268–2270. [PubMed: 10386538]
- Gordon CM. Commentary on meta-analysis of randomized controlled trials for HIV treatment adherence interventions. Journal of Acquired Immune Deficiency Syndromes 2006;43(Suppl 1):S36–S40. [PubMed: 17133203]
- Henry SB, Holzemer WL, Weaver K, Stotts N. Quality of life and self-care management strategies for PLWAs with chronic diarrhea. Journal of the Association of Nurses in AIDS Care 1999;10(2):46–54. [PubMed: 10065409]
- Herek GM. AIDS and stigma. American Behavioral Scientist 1999;42:1106–1116.
- Ho DD. Toward HIV eradication or remission: The tasks ahead. Science 1998;280(5371):1866–1867. [PubMed: 9669944]
- Holman HR, Lorig KR. Overcoming barriers to successful aging: Self-management of osteoarthritis. Successful Aging. The Western Journal of Medicine 1997;167(4):265–268. [PubMed: 9348758]
- Holzemeyer WL, Urs LR. Managing AIDS stigma. SAHARA 2004;1(3):165-174.

Horton R, Das P. Putting prevention at the forefront of HIV/AIDS. Lancet 2008;372(9637):421–422. [PubMed: 18687463]

- House, JS. Work, stress and social support. Reading, MA: Addison-Wesley; 1981.
- Inouye J, Flannelly L, Flannelly KJ. The effectiveness of self-management training for individuals with HIV/AIDS. JANAC: Journal of the Association of Nurses in AIDS Care 2001;12(2):73–84.
- Jack, D. Public attitudes toward HIV. Positive Nation. 2008. Retrieved November 19, 2008, from http://www.positivenation.co.uk/feature/138/welcome138.php
- Janssens B, Van Damme W, Raleigh B, Gupta J, Khem S, Soy TK, et al. Offering integrated care for HIV/AIDS, diabetes and hypertension within chronic disease clinics in Cambodia. Bulletin of the World Health Organization 2007;85(11):880–805. [PubMed: 18038079]
- Jerant AF, von Friederichs-Fitzwater MM, Moore M. Patients' perceived barriers to active self-management of chronic conditions. Patient Education and Counseling 2005;57:300–307. [PubMed: 15893212]
- Kaiser Family Foundation. HIV/AIDS policy fact sheet: The HIV/AIDS epidemic in the United States. 2005. Retrieved September 24, 2007, from http://www.kff.org/hivaids/upload/Fact-Sheet-The-HIV-AIDS-Epidemic-in-the-United-States-2005-Update.pdf
- Kalichman, S. Couples with HIV/AIDS. In: Schmaling, KB.; Sher, TG., editors. The psychology of couples and illness: Theory, research & practice. Washington, DC: American Psychological Association; 2000. p. 171-190.
- Kemppainen JK, Eller LS, Bunch E, Hamilton MJ, Dole P, Holzemer W, et al. Strategies for self-management of HIV-related anxiety. AIDS Care 2006;18(6):597–607. [PubMed: 16831788]
- Kelly JA, Kalichman SC. Behavioral research in HIV/AIDS primary and secondary prevention. Journal of Consulting and Clinical Psychology 2002;70(3):626–639. [PubMed: 12090373]
- Kennedy A, Reeves D, Bower P, Lee V, Middleton E, Richardson G, et al. The effectiveness and cost effectiveness of a national lay-led self care programme for patients with long-term conditions: A pragmatic randomised control trial. Journal of Epidemiology and Community Health 2007a;61:254–261. [PubMed: 17325405]
- Kennedy A, Rogers A, Crossley M. Participation, roles, and the dynamics of change in a group-delivered self-management course for people living with HIV. Qualitative Health Research 2007b;17(6):744–758. [PubMed: 17582018]
- Kennedy, P.; Hopwood, M.; Duff, J. Psychological management of chronic illness and disability. In: Milgrom, J.; Burrows, GD., editors. Psychology and psychiatry: Integrating medical practice. Chichester, UK: John Wiley & Sons; 2001. p. 183-212.
- Kiecolt-Glaser JK, McGuire L, Robles TF, Glaser R. Emotions, morbidity, and mortality: New perspectives from psychoneuroimmunology. Annual Review of Psychology 2002;53:83–107.
- Kiecolt-Glaser R, Exner TE, Correale J, Kirshenbaum SB, Remien RH, Ehrhardt AA, et al. It's not just what you say: Relationships of HIV disclosure and risk reduction among MSM in the post-HAART era. AIDS Care 2007;19(6):749–756. [PubMed: 17573594]
- Knowlton AR, Hua W, Latkin CA. Social support and medical service use among HIV positive injection drug users. AIDS Care 2005;17:479–492. [PubMed: 16036234]
- Kobau R, DiIorio C. Epilepsy self-management: A comparison of self-efficacy and outcome expectancy for medication adherence and lifestyle behaviors among people with epilepsy. Epilepsy Behavior 2003;4(3):217–225. [PubMed: 12791322]
- Latkin CA, Knowlton AR. Micro-social structural approaches to HIV prevention: Asocial ecological perspective. AIDS Care 2005;17:S102–S113. [PubMed: 16096122]
- Lee M, Rotheram-Borus MJ, O'Hara P. Disclosure of serostatus among youth living with HIV. AIDS and Behavior 1999;3:33–40.
- Lee MB, Rotheram-Borus MJ. Parents' disclosure of HIV to their children. AIDS 2002;16(16):2201–2207. [PubMed: 12409742]
- Lightman, S. Can neurobiology explain the relationship between stress and disease? In: White, P., editor. Biopsychosocial medicine: An integrated approach to understanding illness. New York: Oxford University Press; 2005. p. 103-16.

Lohse N, Hansen AB, Pedersen G, Kronborg G, Gerstoft J, Sørensen HT, et al. Survival of persons with and without HIV infection in Denmark, 1995–2005. Annals of Internal Medicine 2007;146(2):87–95. [PubMed: 17227932]

- Looper KJ, Kirmayer LJ. Perceived stigma in functional somatic syndromes and comparable medical conditions. Journal of Psychosomatic Research 2004;57:373–378. [PubMed: 15518673]
- Lorig, K. What are the barriers to healthcare systems using a biopsychosocial approach and how might they be overcome?. In: White, P., editor. Biopsychosocial medicine: An integrated approach to understanding illness. New York: Oxford University Press; 2005. p. 201-215.
- Lorig KL, Ritter P, Stewart A, Sobel D, Brown B, Bandura A, et al. Chronic disease self-management program: 2-year health status and health care utilization outcomes. Medical Care 2001;39(11):1217–1223. [PubMed: 11606875]
- Lorig KR, Sobel DS, Stewart AL, Brown BW, Bandura A, Ritter P, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. Medical Care 1999;37(1):5–14. [PubMed: 10413387]
- Mahajan AP, Sayles JN, Patel VA, Remien RH, Sawires SR, Ortiz DJ, et al. Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. AIDS 2008;22:S67–S79. [PubMed: 18641472]
- Marks R, Allegrante J, Lorig K. A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: Implications for health education and practice. Health Promotion Practice 2005;6(1):37–156. [PubMed: 15574526]
- McDonald, K. Tackling chronic diseases: A conversation with Dr. James Marks. 2003. Retrieved November 18, 2008, from the US CDC Foundation website http://www.cdcfoundation.org/frontline/2003/tackling chronic diseases.aspx
- Merson MH, O'Malley J, Serwadda D, Apisuk C. HIV prevention 1 the history and challenge of HIV prevention. Lancet 2008;372(9637):475–488. [PubMed: 18687461]
- Miles MS, Holditch-Davis D, Eron J, Black BP, Pedersen C, Harris DA. An HIV self-care symptom management intervention for African American mothers. Nursing Research 2003;52(6):350–360. [PubMed: 14639081]
- Miller, J. Living well goes global; Positive Nation. 2008. p. 121Retrieved November 16, 2008, from http://www.positivenation.co.uk/issue121/features/feature4/feature4.htm
- Mitchell CG, Linsk NL. A multidimensional conceptual framework for understanding HIV/AIDS as a chronic long-term illness. Social Work 2004;49(3):469–477. [PubMed: 15281702]
- Murphy DA, Greenwell L, Resell J, Brecht ML, Schuster MA. Early and middle adolescents' autonomy development: Impact of maternal HIV/AIDS. Clinical Child Psychology and Psychiatry 2008;13:253–276. [PubMed: 18540228]
- National AIDS Trust. HIV Statistics in the UK. 2009. Retrieved February 26, 2009 at: http://www.nat.org.uk/HIV-Facts/Statistics/Latest-UK-Statistics/how-manypeople-with-hiv-dying.aspx
- National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP). Chronic Disease Overview. 2008. Retrieved January 28, 2008, from http://www.cdc.gov/nccdphp/overview.htm
- Nicca D, Moody K, Elzi L, Spirig R. Comprehensive clinical adherence interventions to enable antiretroviral therapy: A case report. Journal of the Association of Nurses in AIDS Care 2007;18(6): 44–53. [PubMed: 17991598]
- Ooms G, Van Damme W, Baker BK, Zeitz P, Schrecker T. The 'diagonal' approach to global fund financing: A cure for the broader malaise of health systems? Global Health 2008;25(4):1–7.
- Pew Global Attitudes Project. A global look at public perceptions of health problems, priorities, and donors. The Kaiser/Pew Global Health Survey. 2007. Retrieved February 26, 2009 at http://pewglobal.org/reports/pdf/259.pdf
- Rotheram-Borus MJ, Lee MB, Murphy DA, Futterman D, Duan N, Birnbaum J, et al. Efficacy of a preventive intervention for youth living with HIV. American Journal of Public Health 2001a;91:400–405. [PubMed: 11236404]
- Rotheram-Borus MJ, Murphy DA, Wight RG, Lee MB, Lightfoot MA, Swendeman D, et al. Improving the quality of life among young people living with HIV. Evaluation and Program Planning 2001b; 24:227–237.

Rotheram-Borus MJ, Swendeman D, Comulada WS, Weiss RE, Lee M, Lightfoot M. Prevention for substance-using HIV-positive young people: Telephone and in-person delivery. Journal of Acquired Immune Deficiency Syndrome 1(37 (Suppl: 2)):S68–S77.

- Rotheram-Borus MJ, Flannery D, Rice E, Lester P. Families living with HIV. AIDS Care 2005;17(8): 978–87. [PubMed: 16176894]
- Sackoff JE, Hanna DB, Pfeiffer MR, Torian LV. Causes of death among persons with AIDS in the era of highly active antiretroviral therapy: New York City. Annals of Internal Medicine 2006;145:397– 406. [PubMed: 16983127]
- Sanders C, Rogers A, Gately C, Kennedy A. Planning for end of life care within lay-led chronic illness self-management training: The significance of 'death awareness' and biographical context in participant accounts. Social Science & Medicine 2008;66(4):982–993. [PubMed: 18158212]
- Sankar A, Luborsky M. Developing a community- based definition of needs for persons living with chronic HIV. Human Organization 2003;62(2):153–165.
- Schackman BR, Gebo KA, Walensky RP, Losina E, Muccio T, Sax PE, et al. The lifetime cost of current human immunodeficiency virus care in the United States. Medical Care 2006;44(11):990–997. [PubMed: 17063130]
- Schreurs KMG, Colland VT, Kuijer RG, de Ridder DTD, van Elderen T. Development, content, and process evaluation of a short self-management intervention in patients with chronic diseases requiring self-care behaviours. Patient Education and Counseling 2003;51:133–141. [PubMed: 14572942]
- Schmitt JK, Stuckey CP. AIDS no longer a death sentence, still a challenge. Southern Medical Journal 2004;97(4):329–330. [PubMed: 15108821]
- Scott-Sheldon LAJ, Kalichman SC, Carey MP, Fielder RL. Stress management interventions for HIV–adults: Ameta-analysis of randomized controlled trials, 1989 to 2006. Health Psychology 2008;27 (2):129–139. [PubMed: 18377131]
- Shapiro K, Ray S. Sexual health for people living with HIV. Reproductive Health Matters 2007;15(29 (Suppl 1)):67–92. [PubMed: 17531749]
- Siegel K, Lekas HM. AIDS as a chronic illness: Psychosocial implications. AIDS 2002;16(Suppl 4):S69–S76. [PubMed: 12699002]
- Skinner TC, Carey ME, Cradock S, Daly H, Davies MJ, Doherty Y, et al. Diabetes education and self-management for ongoing and newly diagnosed (DESMOND): Process modeling of pilot study. Patient Education and Counseling 2006;64:369–377. [PubMed: 17011154]
- Smith SR, Rublein JC, Marcus C, Brock TP, Chesney MA. A medication self-management program to improve adherence to HIV therapy regimens. Patient Education and Counseling 2003;50(2):187–199. [PubMed: 12781934]
- Smith TW, Ruiz JM. Psychosocial influences on the development and course of coronary heart disease: Current status and implications for research and practice. Journal of Consulting and Clinical Psychology 2002;70(3):548–568. [PubMed: 12090369]
- Sol BG, van der Bijl JJ, Banga JD, Visseren FL. Vascular risk management through nurse-led self-management programs. Journal of Vascular Nursing 2005;23(1):20–24. [PubMed: 15741961]
- Strauss, AL.; Corbin, J.; Fagerhaugh, S.; Glaser, B.; Maines, D.; Suczek, B., et al. Chronic illness and the quality of life. St. Louis, MO: Mosby; 1984.
- Steptoe, A. Remediable or preventable psychological factors in the aetiology and understanding of medical disorders. In: White, P., editor. Biopsychosocial medicine: An intergrated approach to understanding illness. New York, NY: Oxford University Press; 2005. p. 59-75.
- Swerissen H, Belfrage J, Weeks A, Jordan L, Walker C, Furler J, et al. A randomized control trial of a self-management program for people with a chronic illness from Vietnamese, Chinese, Italian and Greek backgrounds. Patient Education and Counseling 2006;64:360–368. [PubMed: 16859871]
- Thorne S, Paterson B, Russell C, Schultz A. Complementary/alternative medicine in chronic illness as informed self-care decision making. International Journal of Nursing Studies 2002;39(7):671–683. [PubMed: 12231024]
- Tsai Y, Hsiung P, Holzemer WL. Symptom management in Taiwanese patients with HIV/AIDS. Journal of Pain and Symptom Management 2002;23(4):301–309. [PubMed: 11997199]

Uchino BM, Cacioppo JT, Kiecolt-Glaser JK. The relationship between social support and physiological process: A review with emphasis on underlying mechanisms and implications for health. Psychological Bulletin 1996;119:488–531. [PubMed: 8668748]

- UK Department of Health. Chronic disease management: A compendium of information. London:
 Department of Health Publications; 2004. Retrieved November 18, 2008, from
 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/
 DH_062820
- UNAIDS. Report on the global AIDS epidemic: Executive summary. 2008. Retrieved November 17, 2008, from http://data.unaids.org/pub/GlobalReport/2008/JC1511 GR08 ExecutiveSummary en.pdf
- Van Eijk JTM, de Haan M. Care for the chronically ill: The future role of health care professional and their patients. Patient Education and Counseling 1998;35:233–40. [PubMed: 9887855]
- Von Korff M, Gruman J, Schaefer J, Curry SJ, Wagner EH. Collaborative management of chronic illness. Annals of Internal Medicine 1997;127(12):1097–1102. [PubMed: 9412313]
- Willison KD, Andrews GJ. The potential of public health to enhance chronic disease management. Public Health 2003;119(12):1130–1132. [PubMed: 16084543]
- World Health Organization. Innovative care for chronic conditions. Noncommunicable Diseases and Mental Health Meeting Report May 2001:30–31.
- World Health Organization. Chronic diseases and health promotion. 2008. Retrieved January 14, 2008, from http://www.who.int/chp/en/
- Worthman CM, Panter-Brick C. Homeless street children in Nepal: Use of allostatic load to assess the burden of childhood adversity. Developmental Psychopathology 2008;20(1):233–255.
- Wright CC, Barlow JH, Turner AP, Bancroft GV. Self-management training for people with chronic disease: An exploratory study. British Journal of Health Psychology 2003;8(Pt4):465–476. [PubMed: 14614793]

 Table 1

 Chronic illness self-management programs and models: action steps with providers and targeted outcomes.

| Authors/programs | Action st | eps with providers | Targeted | Targeted outcomes | | |
|--|--|--|--|--|--|--|
| Creer, Holroyd, Glasgow, and Smith (2004); review | Goal setting in collaboration with healthcare providers. | | None specified, a generic model for adapting to life challenges. | | | |
| chapter | 2 | 2 Action to promote health. | | | | |
| | 3 | Self-monitoring to gather and record data on a regular schedule. | | | | |
| | 4 | Information processing and evaluating. | | | | |
| | 5 | Self-evaluation. | | | | |
| | 6 | Decision making based on data. | | | | |
| Jerant, von Friederichs- Fitzwater, and Moore | 1 | Formal, careful process applied to problem solving. | 1 | Highly developed partnership with healthcare providers. | | |
| (2005); Homing in on Health Program | 2 | Decision made after carefully weighing options. | 2 | Expertise in identifying and selecting support. | | |
| | 3 | Action planning applied frequently. | 3 | Frequent self-tailoring of medical regime based on physical perceptions of health. | | |
| Schreurs, Colland, Kuijer, de Ridder, and van Elderen | 1 | Specifying necessary conditions for goal attainment. | | Recognizing early symptoms and acting on them. | | |
| (2003); Short self- management intervention for asthma, diabetes, and | 2 | Brainstorming predictable barriers to goal attainment. | 2 | Self-regulated adaptations in medicine. | | |
| heart failure. | 3 | Appraising before acting. | 3 | Following lifestyle and diet recommendations. | | |
| | 4 | Setting individual goals. | | | | |
| | 5 | Acting according to plan. | | | | |
| | 6 | Self-monitoring. | | | | |
| | 7 | Evaluating and either registering goal attainment or going back to revise plan. | | | | |
| Von Korff, Gruman, Schaefer, Curry, and Wagner (1997); review article | 1 | Collaborative definition of problems: patient-defined problems are identified along with medical problems diagnosed by physicians. | 1 | Accessing services that teach skills to carr out medical regimens, guide health behavior changes, provide emotional support. | | |
| | 2 | Develop action plan with realistic objectives. | 2 | Continuing self-management training and support services. | | |
| | 3 | Targeting, goal setting, and planning. | 3 | Successful functioning in social roles and relationships. | | |
| | | | 4 | Maintenance of self-esteem and positive emotional states. | | |
| | | | 5 | Appropriate daily routines based on self-monitoring of physical health status. | | |
| Gifford and Sengupta (1999); Positive Self- | 1 | Identifying and prioritizing needs. | 1 | Managing and adhering to complicated medication programs. | | |
| Management Program | 2 3 | Accessing information. Locating and using available community | 2 | Managing stress-related symptoms. | | |
| | | | 3 | Maintaining or improving physical | | |
| | 4 | resources. Problem solving for interpreting new symptoms. | 3 | function. | | |
| | 4 | | 4 | Optimizing provider-patient interactions. | | |

Table 2

Common elements, tasks and challenges of chronic disease and HIV self-management in physical, psychological, and social domains.

| Physical health: elements | Common across chronic diseases | HIV-specific examples |
|--|---|--|
| Framework for understanding illness and wellness | "Illness coherence" (Skinner et al., 2006) – individual's perception that he/she under-stands their illness. "If I make behavior changes that improve physical functioning, I am reducing the harm caused by disease". | Framing the goal as "strengthening the immune system." "If I adhere to medication regime, maintain healthy behaviors, and manage stress effectively, then viral load will be negligible and my CD4 count will be above 500." |
| Health-promoting behaviors | Goals for controlling body weight, eating nutritious foods, avoiding tobacco use, controlling alcohol consumption, increasing physical activity (Australian Institute of Health and Welfare, 2008). Poverty and lack of access to resources are barriers to healthy behaviors. | Safe sex is still necessary to avoid infection with STI and drug-resistant HIV strains. Drug abuse impairs health and increases probability of risky behaviors. |
| Adherence to medication (and other treatment) regimens | Following medication dosing schedules, planning ahead for refills, and coping with side effects (Knowlton, Hua, & Latkin, 2005). | Adherence challenged by complicated highly active antiretroviral therapy (HAART) medications. Adherence support program includes feedback on adherence through electronic monitoring, and principles of self-regulation, including self-monitoring, goal-setting, and self-incentives (Smith, Rublein, Marcus, Brock, & Chesney, 2003). |
| Self-monitoring of physical health status | Skills to use medical equipment to obtain accurate data: to check blood levels (insulin or cholesterol), blood pressure (hypertension), and breathing (asthma, COPD). Ability to make independent decisions based on self-monitoring data. Data provide feedback on effectiveness of behavior changes (e.g., reduced weight signals success of reduced food consumption and increased activity). Patient learns decision tree for responding to negative data (Fishwick, D'Souza, & Beasley, 1997). | No direct self-monitoring technology for physiological markers is currently available. How to monitor nine common and potentially dangerous symptoms associated with HIV (Gifford & Sengupta, 1999). |
| Accessing appropriate treatments and services | Become knowledgeable about elements of quality care for specific illness and how to access best treatment. Need access to coordination support (i.e., case managers) for providers from different disciplines. | Access to medical care to monitor health status, and access to HAART and other treatments is essential. |
| Preventing transmission | Infectious diseases are chronic when there is no cure. Herpes simplex and hepatitis are infectious and chronic, and evidence is emerging for others (American Society for Microbiology, 2005). | Condom use, not sharing injection equipment, and informing partners of HIV status. Laws criminalizing PLH aware of seropositive status that knowingly put others at risk for infection (Pew Global Attitudes Project, 2007). Sexual health within requirements for protection is goal, rather than avoidance of sexuality (Shapiro & Ray, 2007). |
| Psychological functioning; elements | Common across chronic diseases | HIV-specific examples |
| Self-efficacy and empowerment | Develop feelings of mastery and control over health outcomes; feeling powerless contributes to ill health (Aujoulat, d'Hoore, & Deccache, 2007). Self-management skills contribute to self-efficacy (e.g., over pain and fatigue for people with arthritis) (Lorig et al., 1999). Belief that behavior does not affect health causes medication and treatment regimen non-adherence (Kennedy, Hopwood, & Duff, 2001). | PWH feel powerless and live with uncertainty; self-management goals assert control over disease and life (Gifford & Sengupta, 1999). |
| Cognitive skills of self-management | Planning, contracting, using data in decision making, problem solving, and self-reinforcement for successes. | No difference in skills. |
| Reduction of negative emotional states | Psychological stress influences unhealthy lifestyle choices and affects pathophysiological processes | Relationship of stress to immune system (Cohen, Frank, Doyle, Skoner, & Rabin, 1998; Glaser, |

| Physical health: elements | Common across chronic diseases | HIV-specific examples |
|--|---|---|
| | Steptoe, 2005). Anxiety and depression may be caused by the disease, medication side effects, and/ or emotional distress (Kalichman, 2000). Stressmanagement skills are necessary element of interventions. | Kiecolt-Glaser, McGuire, Robles, & Glaser, 2002) makes stress management an important protective strategy. High levels of depression and anxiety are associated with HIV; mothers and pregnant women who are HIV-seropositive have extra burdens increasing negative emotions and stress (Rotheram-Borus, Flannery, Rice, & Lester, 2005). |
| Identity | Normalization process – being seen as normal and engaging as much as possible in normal living (Charmaz, 1991). "I have a chronic illness that I can learn to manage in order to increase my lifespan and improve the quality of daily life." Illness can be integrated into life as "illness work" (Strauss et al., 1984). Health promoting behaviors become integrated with personal values and sense-of-self (Bellg, 2003). | Stages of identity development may include immersion in activist community (Baumgartner, 2007); "Striving for normalcy" rather than either concealing HIV or making it center of identity (Chenard, 2007). |
| Social relationships: elements | Common across chronic diseases | HIV-specific examples |
| Collaborative relationships with health care professionals | Empowerment of patient means changing the roles in the traditional medical system (Anderson, 1995). Patient is active in decision making (Aujoulat et al., 2007; Van Van Eijk & de Haan, 1998). "Partnership" between patient and healthcare professional (Holman & Lorig, 1997). Focus on communication skills for patient–professional relationship (Lorig et al., 1999). | PWH need to find health professionals who are comfortable with HIV disease. |
| Self-disclosure of disease status and coping with stigma | Stigma is associated with many chronic diseases, including epilepsy (Kobau & Dilorio, 2003) and chronic fatigue syndrome (Looper & Kirmayer, 2004). Obesity, associated with chronic diseases such as diabetes and osteoarthritis, is a stigmatized condition. | Greater stigma with HIV than other diseases. Concealing HIV infection decreases availability of social support (Herek, 1999). PWH face challenge of when and how to communicate with potential romantic partners. Failure to disclose HIV status to partners may be motivated by fears of abandonment, abuse or violence (Kalichman, 2000). Stigma management strategies: selective disclosure and preemptive disclosure (Bellg, 2003). Selective self-disclosure is a later stage of adjustment (Beaudin & Chambré, 1996). Involvement with HIV-specific service organizations provides environment without stigma threat (Bellg, 2003). |
| Positive social and family relationships | Supportive family is protective against stress, while poor family relations can contribute to stress. Family members can take on tasks of helping patient, reinforce health-promoting behaviors, and contribute to information gathering and good decision making. Being in a committed romantic relationship improves coping with illness. Caregiver stress can lead to patient mistreatment and emotional and health problems in the caregiver. | Sharing information with family and friends reduces HIV stigma and fear of contagion. Different challenges for seroconcordant and serodiscordant couples (Kalichman, 2000). |
| Social support | Four types of support: (1) social (e.g., esteem, affect, trust, concern, and listening); (2) positive appraisal; (3) informational (e.g., advice, directives, and information); and (4) instrumental (e.g., supplies, tools, and money) (House, 1981). Social role and position in social networks influences choice of health promoting or risky behaviors. Social isolation has been associated with impaired immune system functioning (Cohen et al., 1998). Peer leaders provide modeling: "I have lived with this disease and I can teach you how to live it" (Lorig, 2005). | Seek positive and affirming social networks as a form of self-care (Chenard, 2007). Beneficial to have at least one group leader in prevention programs be HIV positive (Gifford & Sengupta, 1999). Targeting PLH's support network members may help de-stigmatize HIV and increase healthy behaviors (Knowlton et al., 2005). Special needs of drug users and mothers (Latkin & Knowlton, 2005). |