Making Sure HIV Patient Self-Management Works

A Training Workshop for HIV Care Providers
Curriculum Guide for Workshop Facilitators

New York State Department of Health AIDS Institute
Health Resources and Services Administration HIV/AIDS Bureau

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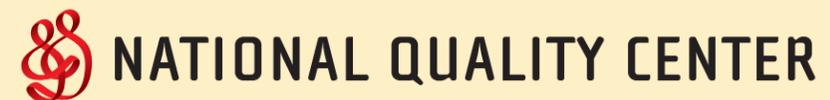
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Curriculum Guide for Workshop Facilitators

Developed by the
New York State Department of Health
AIDS Institute

For the
Health Resources and Services Administration
HIV/AIDS Bureau

Prepared by Joseph Rukeyser, Ph.D.

January 2008

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Acknowledgements

The New York State Department of Health AIDS Institute has supported the development and maturation of the concept of patient self-management in HIV care and has promoted the integration of patient self-management practices into the routine care of patients with and at risk for HIV/AIDS. The AIDS Institute's Quality of Care Program and its Provider and Consumer Advisory Committees have contributed valuable insights, experiences, and practical suggestions in the development of this training curriculum. For their efforts, we extend our special thanks.

The training curriculum was written by Joseph Rukeyser, Ph.D. Activities used in this curriculum are based in part on activities that have been used in delivering trainings to consumers in the consumer training workshop curriculum, "Making Sure Your HIV Care is the Best It Can Be."

Our sincere thanks to the many health care providers who reviewed and commented upon drafts of this curriculum and who participated in the pilot tests and revisions of the curriculum.

This publication, the consumer companion curriculum ("Making Sure Your HIV Care is the Best It Can Be") and a related literature search on this important topic are available online at our website at NationalQualityCenter.org. Additional hardcopies can be ordered by calling 212-417-4730. We welcome your suggestions and ideas for future editions.

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Introduction

Introduction to Patient Self-Management

Patient self-management is the ability of patients, in a complementary partnership with their health care providers, to manage the symptoms, treatment, and lifestyle behavior changes, as well as the physical and psycho-social concerns, that are a part of living with chronic diseases. Some patients manage these responsibilities well. Others have more difficulty. Nevertheless, all patients with chronic diseases manage their illness on a daily basis, and most patients have the ability to develop the skills, attitudes and understandings to make decisions and to take actions appropriate to their lives and their health status. (Anderson and Funnell, 2000; Von Korf et al, 1997)

Provider support for patient self-management is a key element in determining how well patients make appropriate decisions and take appropriate actions to promote their health and well-being. (Coleman and Newton, 2005) Clinical providers support patient self-management through establishing an effective care partnership with patients. Collaboratively, clinicians and patients engage in identifying and overcoming barriers to the patient's optimal health and health care, utilizing available resources, improving patient self-efficacy, and improving the patient's understanding of their disease as well as their ability to interact effectively with members of the health care team. (Coleman and Newton, 2005)

Patient self-management programs have been developed over the last decade to assist patients with chronic diseases in taking greater control of the day-to-day management of their health and health care. (Bodenheimer et al, 2002) These programs have proven to be successful in improving health outcomes among patients with chronic diseases such as diabetes, asthma, chronic arthritis, and congestive heart failure. Improvements have been reported in patient self-efficacy, health outcomes, and quality-of-life among patients with chronic diseases. Some programs have also proven effective in reducing health care costs and emergency room visits, and in improving adherence with chronic disease self-monitoring, medication and treatment regimens. (Bodenheimer et al, 2002) Self-management initiatives incorporate principles of cognitive-behavioral intervention, patient empowerment, adult patient education, collaborative care, and shared health care decision-making.

HIV/AIDS as a Chronic Disease

With the development of effective long-term combination medical therapies and disease monitoring protocols which can significantly slow disease progression, HIV/AIDS shares some important similarities with other chronic diseases. (HRSA 2006) Many of the problems associated with the management of HIV disease, as seen from the perspective of patients (e.g., adherence to regimen, management of disease symptoms and side-effects, provider-patient communication), clinicians (e.g., patient disease education, medication and scheduled visit adherence) and program administrators (e.g., emergency room visits), appear amenable to change through the application of self-management interventions. In addition, many people with HIV infection are also living with other chronic illnesses such as hypertension, hyperlipidemia, and diabetes. (Aberg 2006)

The Need for Provider-Centered Training

Clinical provider training in patient self-management programs is primarily focused on methods of disease education and behavioral skills development for patients and delivered by trained educators and peers in courses that may span several weeks. We are aware of no training programs for HIV health care providers that prepare them for supporting patients in collaborative self-management planning and in implementing self-management plans of action. This curriculum has been designed for delivery in a two and one-half hour workshop. Depending upon the training experience of the facilitator and the availability of materials, preparation for each training may require about one hour.

Introduction to the Curriculum

This curriculum is designed to provide a brief, interactive, skills-based training program to help HIV/AIDS health care providers gain a more thorough understanding about patient self-management concepts and practices.

Care providers will learn ways to work collaboratively with HIV/AIDS patients in setting self-management goals, problem-solving, resource utilization, action planning and self-assessment. Providers will be trained to identify, evaluate, and utilize patient self-management support programs and materials in their practices.

Curriculum Goal

The goal of this training program is to improve the quality of health care for HIV/AIDS patients by fostering an increased collaborative interaction between patients and their providers and increasing patient self-efficacy.

The curriculum is designed to be used in training clinical care providers (e.g.,physicians, nurses, nurse practitioners, physician assistants) and non-clinicians (e.g.,case managers, medical social workers, treatment educators) who provide patient care to people with HIV/AIDS.

Curriculum Objectives

Upon completing the training workshop, participants will be able to:

- Describe the concepts which underlie the patient self-management paradigm
- Identify the characteristics of effective self-managers
- Evaluate the potential use in their own practice settings of self-management supports and interventions
- Develop self-management support tools which meet the particular needs of their patients and characteristics of their practices
- Engage in collaborative goal-setting, decision-making, action-planning, and behavior change education with patients
- Develop an action plan for the integration of patient self-management supports into their practice settings

Use of the Curriculum

The learning experiences in this curriculum consist of interactive, learner-centered activities that are intended for delivery by trained educators. No clinical training is needed or is expected for the effective delivery of the entire curriculum. However, an awareness and appreciation for the demands, pressures, and stresses faced by clinicians in the course of providing medical care for people with HIV/AIDS is an asset. It is suggested that the educator review the recommended readings listed at the end of this curriculum before delivering the training. Also, it may be beneficial, though not necessary, for participants to be familiar with the key readings that support the curriculum.

The curriculum has been structured around the sequential delivery of activities as they appear in this guide. Given the time constraints common in clinical education programming, the training workshop may be delivered in a single session or in two or more sessions.

It is recommended that if multiple sessions are used, the sequence of the activities be maintained.

In each of the training activities you will find:

- an educational rationale
- facilitator notes
- materials needed
- approximate time required for delivery
- procedure
- templates for instructional materials

Workshop Evaluation

A workshop evaluation form is provided for post-program assessment of participant satisfaction and comments. The program self-assessment should be filled out by participants prior to workshop participation and the post-program self-assessment should be completed at the conclusion of the training.

Further Information

In addition to this curriculum, the following resources are available from the New York State Department of Health:

- Annotated bibliography of selected publications pertaining to patient self-management in HIV care and in other chronic care diseases (see Appendix)
- "Making Sure Your HIV Care is the Best It Can Be"; a patient/consumer training curriculum in quality of care and self-advocacy skills
- "A Guide to Consumer Involvement: Improving the Quality of Ambulatory HIV Programs"; a publication that outlines descriptions, rationale, and implementation ideas for proven and effective methods of promoting and enhancing HIV/AIDS consumer involvement
- "Patient Health Journal"; a journal for HIV-infected patients to maintain their own health record and facilitate the exchange of medical information
- National Quality Center's consumer involvement web-page with a collection of training curricula and publications on consumer involvement across the country
- The "Patient Satisfaction Survey for HIV Ambulatory Care"; a publication specifically for HIV primary care providers to help them capture patient feedback which enhances quality improvement efforts.

To access these and other resources, please visit our website at NationalQualityCenter.org or order them by calling us at 212-417-4730. If you have additional resources or are aware of others, please contact us so that they might be shared on our website.

Activity 1:

Introduction to The Workshop

Rationale:

In this introduction to the training, participants will become oriented to the objectives and processes of the workshop. They will have an opportunity to meet the other workshop participants, to clarify their learning goals for the workshop and to learn that others in the group share similar concerns and learning objectives about patient self-management. As the facilitator you will gain an understanding of the initial concerns and attitudes of the participants.

Materials Needed:

• Newsprint Sign:

Welcome to
"Making Sure HIV Patient Self-Management Works"
Provider Training
Facilitator Name:_____
Time of Training Start and End:_____

• Masking tape
• Newsprint pad
• Easel
• Markers for newsprint
• Pre-written newsprint list of "Workshop Objectives"

Time needed:

20 minutes

Procedure:

1. Hang the workshop title newsprint sign where all participants can see it when they come into the training room.
2. Welcome the group of participants to the workshop when all have arrived.
3. Introduce yourself and your role as the workshop facilitator.
4. Describe the purpose of the workshop:

The goal of this workshop is to provide a brief, interactive, skills-based training to help you gain a more thorough understanding of patient self-management concepts and practices.

You will learn ways to work with your patients, depending upon their needs, in helping them to set their self-management goals, problem-solve, identify and use their own resources, and engage in action planning and self-assessment.

We will also help you to identify, evaluate, and use effective patient self-management tools in your practice with patients.

5. Describe the timing of the workshop and any "ground rules" (e.g., use of cell phones, limits on side conversations, etc.) or "housekeeping issues" (e.g., location of bathrooms, break times, etc.) that they should know about.

6. Answer any questions about the workshop in general, without getting into any detailed discussion about the workshop content.

7. Tell the participants that:

> This workshop consists of a series of interactive activities. You will all play an important role in shaping the workshop to best meet your own needs as well as in supporting one another in learning about patient self-management.

"Introductions" Activity

8. You may ask the participants to arrange their chairs in a circle, if the room space permits.

9. Explain that you would like them to introduce themselves to one of the people sitting next to them and, in order to make the introductions to the larger group interesting, you want them to tell one another what you most hope to learn in the workshop on patient self-management.

10. Explain that each of them will have about two minutes to "interview" their partner and then they will switch the role of interviewer. When they have learned about one another, they will introduce their partner to the larger group. They will each be asked to tell the group their partner's name, a little bit about them and what their partner wants most to learn about patient self-management today.

11. Ask them to begin interviewing one another and then remind them to switch roles after about two minutes.

12. When all have been interviewed, ask them to come back together as a group and then ask them to introduce their partners to the group.

13. Write each learning goal for the workshop on the newsprint as they are voiced by the participants. Use summary phrases where possible and try not to duplicate items on the list.

14. When all have been introduced, ask if there are any additional learning goals for the workshop and write them on the newsprint.

15. Review with the group the personal learning goals on the newsprint list.

16. Review with the group the overall learning objectives of the workshop, reading from the pre-written newsprint sheet and identify any workshop learning objectives that were not covered in the personal learning goals of the participants.

17. Identify, where appropriate, the personal learning goals that are beyond the scope of the workshop and which will not be met in this workshop. Let them know that later in the workshop we will help them to identify other resources that they might use to meet those goals. [This will likely take place in the discussions around the "Action Planning Activity" at the end of the workshop.]

18. Ask the participants what they have learned so far in the workshop. [Some probable learnings may include: a prior understanding of what patient self-management is; the realization that many others share the same concerns they have or have the same learning objectives regarding patient self-management.]

19. Thank the participants for "getting into" the process of interactive learning so easily and for sharing their thoughts with the group.

There are just a few ground rules that I will ask that we all agree to before we begin.

There are no right or wrong answers to many questions. We all may have different views on what we will be talking about today. It is important to respect and, hopefully, learn from our differences. Only one person will speak at a time, and everyone will have an opportunity to be heard.

Much of what we will do today involves group participation. If, at any time, you don't feel like participating, that decision is up to you and no one will require you to do so.

We have a lot to cover in the workshop. I will try to keep us on time. So, please don't be offended if I interrupt you and ask the group to move on. We can talk more after the workshop is over, if you'd like.

There will be a ten–minute break about half-way through the workshop.

Do you have any other suggestions for ground rules? Let's have a good time today.

Activity 2:

Health Care Self-Management Continuum

Rationale:

Participants will develop, through active involvement and group discussion, an operational definition of self-management. They will see that self-management skills are part of everyday living and that some of them are more effective than others in managing their own health. This activity is also designed to help reduce the separation they may feel between themselves and their patients by having them focus totally on their own health and not on their role as a health care provider. A definition of patient self-management that is a composite of those generally discussed in the published literature is:

"Patient self-management is the ability of patients, in a complementary partnership with their health care providers, to manage the symptoms, treatment, and lifestyle behavior changes, as well as the physical and psycho-social concerns that are a part of living with chronic diseases."

The definition that the participants develop, while likely to be different from this, should reflect a similar acknowledgement of physician-supported patient-centered decision-making and day-to-day patient management of their health. Participants should be encouraged to consider incorporating similar components.

Materials Needed:

- An open space in the room for participants to stand and form a line
- Masking tape
- Newsprint pad
- Easel
- Pre-written newsprint sheet "Workshop Self-Management"

Time Needed:

40 minutes

Procedure:

1. In this activity, participants will be asked to find a place to stand on an imaginary line. The line represents a continuum of satisfaction with their own personal health self-management.

2. Introduce the activity:

This activity is the Health Care Self-Management Continuum. Each of us manages our own health care. We make appointments with physicians and we do our best to keep those appointments. We communicate with our providers, we do our best to follow prescribed treatment plans, we eat, exercise and manage our stress the way we want, and we plan for changes we think we need to make. Some of us do these things more or less effectively than others. In this activity, you will have the opportunity to rate your satisfaction with your own

health self-management. You will do that by actually putting yourself at some point along an imaginary line that represents a range of degrees of satisfaction.

If you are unsatisfied with how well you manage your own health I want you to stand near this end of the continuum (point to one end of the line). On the other hand, if you are very satisfied with how well you manage your own health stand near this end of the line (point to the opposite end of the line). If your level of satisfaction is somewhere in the middle, then find a spot that best shows how you feel.

Before you move, I want you to think for a just a moment about what you do well (and less well) to manage your own health and then stand in the spot that bestrepresents your own self management. Keep in mind that this activity is about how you perceive how well you manage your own health and health care.

3. Allow the participants a few moments to find a place to stand.
    [Note: Some of the participants may find the term "self-management" too vague and they may ask for clarification. They may want you to tell them what aspect of health care you want them to rate. Tell them to use whatever definition of self-management they want.]
4. When people get settled along the line:

Let's pause for a minute to look at where people are standing. As you can see, people are standing in different places. There is clearly some diversity in how people rate their effectiveness in managing their own health. Some people are very satisfied and others are not.

[Note: Pause for a moment so that the group can take notice of the differences within the group.]

Look around and see the other people standing near you. These people rate their abilities as health self-managers about the same as you do.

Take a few moments and talk to those near you about why you have chosen to stand where you did. Where possible, be as specific as you can about the things you do (or don't do) that are part of managing your own health.

5. Allow the participants a few minutes to discuss with each other the reasons that they are standing where they are.

6. When they have had a few minutes to discuss in their small groups, ask a few participants to share the reasons they rated their own health self-management the way they did. Ask, where appropriate, for them to be as specific as possible and to give some examples if they can.

Some examples of specifics might be:
- I always make a list of things I need to talk to my own doctor about before a visit
- I feel that I don't have enough time to make an appointment to see a doctor myself
- I sometimes forget to take a full course of an antibiotic
- I always ask for a copy of my lab results
- I take a stress break everyday
- I have started to drink one less cup of coffee each day

If they do not mention some of the aspects of health self-management listed here, you might mention one or two and ask them about how well they manage these aspects of care.

[Note: You might start at one end and then move along the continuum. It is not necessary to ask each participant to explain why they chose to stand where they did but be sure to ask representatives from each general area along the continuum.]

7. As each participant identifies what they do or do not do well to manage their own health, list them on the newsprint sheet pre-labeled: "Health Self-Management." The components the participants identified as part of their own health self-management form an operational definition of health self-management.

8. When finished with the list ask the participants to move back to their seats. Then ask the group to summarize the categories of self-management tasks that people can pay attention to in order to be more effective health self-managers (e.g., mental health, physical health, communication skills, problem solving, goal-setting and action planning, decision-making, etc.). List on a newsprint sheet the categories of self-management concern identified by the participants. Ask the participants for any additional items or changes to the list.

9. Ask the participants, based upon this discussion, to suggest components of a definition of "self-management." Write the definition(s) on the newsprint. [The definition should be similar to: "Patient self-management is the ability of patients, in a complementary partnership with their health care providers, to manage the symptoms, treatment, and lifestyle behavior changes, as well as the physical and psycho-social concerns that are a part of living with chronic diseases."] Hang this definition on the wall or display it where all participants can see it.

10. In conclusion, ask the participants to share some insights they learned through this activity.

Activity 3:

Patient Self-Management Case Study

Rationale:

We developed an operational definition of patient self-management in Activity 2. In this activity participants will discuss the possible roles of providers in supporting effective self-management through the use of a case study involving two patients with a similar medical history but with different approaches to managing their health.

Materials Needed:

- Andrew and Zeke Case Study Worksheet
- Masking tape
- Newsprint pad
- Easel
- Marker for newsprint

Time needed:

35 Minutes

Procedure:

1. Explain that they have, by working together, developed an operational definition and understanding of the components of effective self-management:

> We will now examine a case study involving two brothers who share similar medical histories but who have very different health outcomes.
>
> This activity is a small group activity. You will each be given a case study to read and then you will have a few questions to answer that will guide your discussion of the case in your group.

2. They will have ten minutes to discuss the case and to answer the questions.
3. The first task of the group will be to select one person to take notes for the small group and to report back to the larger group on the results of their discussion.
4. Ask the participants to form small discussion groups of three to five members.
5. Hand out the "Andrew and Zeke: Case Study" worksheet (pg. 21) and ask the participants to read the case and the related questions. Then take ten minutes to discuss the case.

6. When ten minutes have elapsed, ask the participants to turn their attention to the whole group.

7. Ask the representatives of each of the groups to report back on the discussion question responses. Discuss each question fully before moving on to the next question. You may ask one or two groups to report on each question and then ask if there are any additional discussion points to be added by the other groups.

8. Write the major responses to each question on a separate newsprint sheet.

9. When you have finished the discussion for the three questions, ask the group to summarize the key learnings from this case study. Write these on a newsprint sheet.

10. This case study should be used to identify the various physical, social, psychological, and behavioral factors that contribute to different patients' abilities to manage their health and health care and to prepare the participants to discuss the way that clinicians can help patients to better manage their health by addressing the most important concerns of their patients.

Case Study: Andrew and Zeke

Andrew is a 45 year old active carpenter whose father and mother both died of acute myocardial infarctions at 53 and 59 years of age, respectively. He is married and has a 14-year old daughter.

Andrew's medical history includes dyslipidemia, glucose intolerance, and hypertension. He has never reported any respiratory or cardiovascular complaints and rates his own health as good to excellent. He is a former smoker, having quit six years ago after smoking about a pack a day for twenty years. He reports limited alcohol and caffeine use and has never taken illicit drugs.

Andrew is 5' 10" tall and his weight is within the normal range for his height. He is allergic to aspirin and seafood. Andrew has medical insurance through his employer.

Zeke, Andrew's younger brother, is 42 years old and shares the same family history with his brother. Like Andrew, Zeke's medical history includes dyslipidemia, glucose intolerance, and hypertension.

Zeke is a clerk in the Department of Motor Vehicles and commutes to work using public transportation. He is 5'11" tall and is approximately 15 pounds over recommended weight. He is a one pack-a-day smoker and reports having five to ten alcoholic drinks per week. He drinks coffee and reports that he eats a high fat, low fiber diet.

Zeke is divorced and cares for his developmentally disabled son with serious behavioral problems. He is aware of his medical problems but does not feel he can address them at this time. He has medical insurance provided through his employer.

Both Andrew and Zeke make and keep regularly scheduled appointments with a family practitioner.

Both Andrew and Zeke have recently been added to your patient panel due to a re-organization of the clinical staff.

[This case study is adapted from a case discussion originally presented in Bodenheimer T, Lorig K, Holman H, et al. Patient Self-management of Chronic Disease in Primary Care. JAMA. 2002;288:2469-2475.]
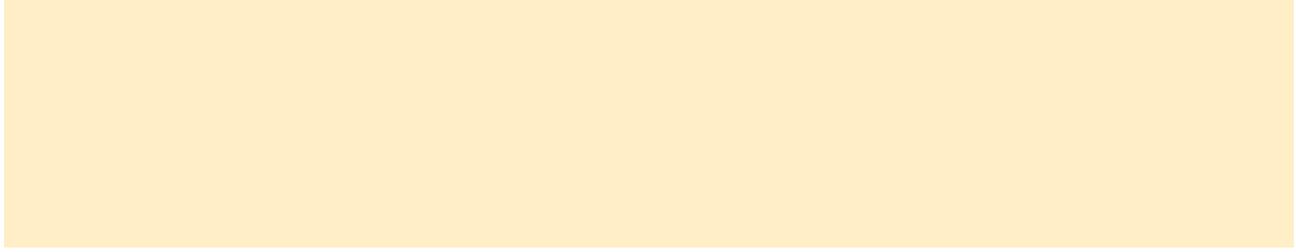
1. What factors are likely to account for the health status differences we see between the two brothers?

    _____

    _____

    _____

    _____

2. What more information about Zeke might help you in working collaboratively with him on improving his ability to manage his health? How might you best get that information?

    _____

    _____

    _____

    _____

3. How would you approach Zeke to help improve his ability to better manage his health? What would you do first?

    _____

    _____

    _____

    _____

Activity 4:

The "To-Do" List

Rationale:

Patients with HIV infection often have a constellation of health problems, some of which are HIV-related and others which are not directly related to HIV but may affect their HIV health management. We now follow the case of Zeke, whom we met in the first case study, after he tests positive for HIV, and discuss the complex management of his care, identifying, in particular, those responsibilities that fall primarily upon Zeke but which may require provider support for optimal management.

Materials Needed:

- Case Study II: Zeke Worksheet
- Masking tape
- Newsprint pad
- Easel
- Marker for newsprint
- Post-it type note cards or index cards (8½" X 5½")
- Felt-tip markers for cards
- Category "Heading" cards prepared ahead of time

Time needed:

45 Minutes

Procedure:

1. Remind participants that:

   > In the case of Andrew and his brother Zeke we identified potential barriers that affect the ability of a patient to effectively manage their own health and to work collaboratively with their health care providers to set and reach realistic health care goals.
   >
   > In this activity we will continue to discuss Zeke's case as it develops and to use it to identify the many tasks or responsibilities that both clinicians and patients can assume in effectively helping patients better manage their health.

2. Ask the participants to once again form small groups of 3-5 members. Ask them to form groups that include some members that are new to the group (to add some fresh ideas). One way to accomplish this is to ask one member of each group to move to the next table (or grouping) in a clockwise fashion.

3. When the new groups are formed, ask the members to identify a new recorder/reporter for the group.

4. Hand out the "Case Study II: Zeke" worksheet and ask the participants to read the case study, discuss it among themselves and answer the questions at the end of the case study. Inform the groups that they will have ten minutes to discuss the case and formulate their answers. When finished, group reporters will be asked to report the answers to the whole group.

5. After ten minutes have elapsed, ask the groups to turn their attention back to the whole group for discussion.

6. Ask the reporters of each group in turn to respond to the first question asked in the case study. Review and discuss their responses. Write the key responses on a newsprint sheet.

7. In response to the last question (The "To Do" List: Identify the tasks that you believe should be undertaken by Zeke and his HIV care team to help Zeke to manage his health and achieve better health outcomes) ask the participants to tape the cards with "tasks" they have written on them on the wall (or newsprint sheets) under each of the following headings: "Medical Care," "Psycho-social," "Physical," "Health Behavior," "Communication," and "Self-Efficacy."

Some examples of possible tasks may be:
- "take meds as prescribed"
- "make and keep MD appointments"
- "arrange for childcare for son"
- "review labs"
- "take stress management class"
- "join patient support group"
- "buy condoms"
- "see adherence counselor"
- "take stress management class"
- "monitor medication side effects"
- "check BP and blood sugar each day"

8. When all of the task cards have been placed under the headings, ask if there are any additional tasks they can think of or if any of the cards should be moved to another heading. Add or move cards if there are any changes to be made.

9. Read the cards aloud, removing duplicates, and clarifying terms if they are unclear. Acknowledge the many and varied tasks that might be needed to help Zeke to become healthier and maintain control of his health.

10. Tell the participants:

> Now we will move the cards one more time. This time we will categorize them under two new headings: "Provider's Control" and "Zeke's Control."
>
> [Keep a separate heading card labeled "Both" ready in the likely case that the group decides that some tasks are shared tasks and then add it to the board.]

11. Ask for three volunteers to come to the board and to move the cards under one or the other of the new headings. They can work independently or they can work as a group to re-categorize the cards. Each card, before it is moved should be shown to the group and then moved. You might encourage the other participants in their seats to provide support or advice to those who are moving the cards.

12. When all of the cards have been re-categorized, ask the group to describe the results. Acknowledge that some tasks are clearly under the team's control and others are clearly tasks that only Zeke can control; still others are shared tasks. [It is likely that the majority of the tasks will be those that are under the "Zeke's Control" heading.]

13. Ask the participants to describe the implications of having a long list of tasks under "Zeke's Control." You might ask:

> How do you feel about the list of tasks that you have placed under "Zeke's Control" and, given what you know about Zeke, how well do you think that Zeke would do with these tasks, if left on his own?

14. Ask the group, "Without getting into specific details, what do you think would help Zeke, and you as his HIV provider, to better accomplish these tasks?" Write the responses on a newsprint sheet.

15. Tell the group that in the next activity we will identify ways that we can work with Zeke and with other supports to begin to take control of these tasks.

16. Leave the cards in their categories on the board or newsprint sheets where participants in their seats can see them as they work on the next activity.

Case Study II: Zeke

Zeke has been informed by a public health partner notification counselor that one of his past sexual partners has tested positive for HIV and that he should consider getting tested himself. He tells you that he does not believe it is possible for him to have HIV but that he wants to be sure and to get tested. You arrange for counseling and testing and the test results come back positive. Zeke says that he is shocked and that he feels that his life is over. He is most concerned about how he will care for his son if he gets very sick.

You suggest that he sees a counselor at a local HIV community-based organization and to make an appointment to see you again to talk about his medical care in a couple of weeks.

Zeke misses this appointment with you but calls to re-schedule an appointment several weeks later.

Zeke shows up for his appointment with a bag full of booklets and brochures about HIV and AIDS that he was given by the counselor. His mood seems to be more positive though he does not look well and admits that he has not been taking good care of himself.

What are your top 3 medical priorities in addressing Zeke's medical care at this time?

1. _____
2. _____
3. _____

Zeke's initial HIV viral load, CD4+ cell, and drug resistance test results indicate that he is a good candidate for antiretroviral therapy. He believes that he is ready to start treatment. You discuss several treatment options with him and agree to proceed with developing a treatment plan and starting ARV therapy.

The "To-Do" List:

What specific tasks do you believe should be undertaken by Zeke and his clinical care team to help you and Zeke to manage his treatment and achieve better health outcomes?

It may help to think of tasks in each of the following categories: "Medical," "Psycho-social," "Physical Health Behavior," "Management Communication," and "Self-efficacy." Write each separate task on one of the colored index cards provided. Write large enough for it to be read by others in the room.

Activity 5:

Patient Self-Management Support

Rationale:

In Activity 4, participants identified a list of major tasks that should be accomplished in order for patients with HIV and other health-related problems to effectively manage their health and health care. Some of these tasks are clearly in the hands of the patient. Nevertheless, they are important and clinicians know that they must be accomplished in order to give the treatment plan a chance of being successful. Patients and clinicians can benefit from materials and program supports that help patients to effectively accomplish these tasks. This small group activity provides an opportunity for participants to identify the patient self-management supports that they think would be most helpful to them and their patients. There are likely to be participants with some experience in the use of patient self-management support tools or programs, and they should be encouraged to share their experiences with others in the group.

Materials Needed:

- Masking tape
- Newsprint pad
- Easel
- Marker for newsprint
- Colored index cards (8½" X 5½")
- Felt-tip markers for cards
- Self-management Support List

Time needed:

40 Minutes

Procedure:

1. Review with the whole group the "To Do" list of tasks that they developed in the previous activity. If, in the previous activity, you did not divide the tasks into three groups ("Providers' Control", "Zeke's Control", and "Both"), ask the group if any of the tasks might better fall under the heading of "Both." If so, move the cards under the new heading. [Encourage them to do so. It will be helpful to this activity to have at least one task under the "Both" heading.]

2. When the cards have been moved, tell the group:

As you can see, many of the tasks or responsibilities we have identified are complex or may take place over time. In these cases, reminders, additional information, or the help of others may be necessary or valuable. In these cases patients, and providers as well, might benefit from support materials or programs (such as lists of action steps, calendars, contact numbers, visit planners, information packets, group visits, etc.).

Some of you may have already had some experience with the use of support materials or the services of other personnel or programs to help patients accomplish self-management tasks. This is where your experience will be most valuable. Please share it with others, if possible.

I would like you now, in each group, to select one task from each of the three categories ("Zeke," Provider," and "Both") and brainstorm all of the support tools that you think would be most helpful to you or "Zeke" in accomplishing or completing each task. Write them down on a list for the group. Then discuss and rank, within the group, the top three things (support tools or help from others) that you, as a group, believe would be most

helpful. There is a list of sample tools that others have developed that we might consider using. [Hand out Sample Patient Self-management Support Tools list.]

For now, don't let barriers like cost or the need to convince others keep you from ranking a tactic highly. We'll talk about dealing with those issues later. For now just make a note of them.

3. Tell the group that they have 10-15 minutes to identify and rank their top 3 tactics for each task.
4. When 10-15 minutes have elapsed, ask the participants to turn their attention back to the whole group.
5. Ask the group reporter from each group to come to the front of the room and to select the card for each task they brainstormed tactics and tape it to the top of a new newsprint sheet. Then ask for a volunteer to write down the top three tactics for helping to accomplish the task on the sheet as the reporter describes them. (If necessary, you may have to do this yourself.)

6. It may be best to ask each reporter to select one of the tasks they worked on and to discuss the tactics for that task. If time permits, you can ask for additional examples. Try to encourage the discussion of least one task from each of the three categories.

7. After the tactics have been described for each task, ask the group if any of them have had experience with that or a similar tactic and to describe how well it worked and, possibly, why it did or did not work well.

8. Ask others for their thoughts on the tactic and how it might be made to work best or under what circumstances it might be most helpful.

9. If there are comments on why a particular tactic might not work, ask the group to suggest ways of making it work better. Ask the reporter (or the group) what barriers are most likely to be a problem for each task and then ask the group for suggestions on how best to overcome that barrier.

10. When the groups have discussed at least one tactic from each heading, you may ask the group for any other tasks or tactics they would like to present to the group for discussion.

11. When finished, call the attention of the whole group to the many self-management support tactics they have come up with, and ask the group if there are any that they found particularly interesting or helpful.

Sample Patient Self-Management Support Tools

Patient-Centered Support:

- Patient orientation to practice (a guidebook and/or group face-to-face meeting)
- Staff contact list (a handout list of who to contact for particular concerns)
- A patient guide or personal "navigator"
- Visit planner worksheet (who to see, time, place, key concerns, questions to ask, what to bring with you)
- Group visits
- Patient Health Journal (a patient's record of key medical record information)
- Patient diary of self-care and questions
- Disease-management education handouts
- Medication guide
- Personal action plan worksheets
- Disease-specific education session
- Patient training in negotiation and communication skills
- Treatment and life-goals planner
- Daily activities checklist
- Patient visit partner/buddy
- Goals and actions contract with patient
- Peer support group and/or peer education program

Provider-Centered Support:

- Visit-preparation planner (completed by provider or staff member before patient visit)
- Pre-physician and post-physician visit with a nurse or patient educator
- Patient concerns checklist (completed by provider after pre-visit with patient to be used by physician as a guide to current patient concerns)
- Assessment tool for patient understandings, perceptions, psychosocial issues, self-efficacy, etc.
- LEARN model guide for cross-cultural communication (Listen, Explain, Acknowledge, Recommend, and Negotiate)
- Action planning form
- Goals and actions contract form
- Getting to 7 (a patient self-efficacy rating scale used in action planning)
- Communication quality checklist (to self-assess the quality of communication with patient during a visit)
- Patient-centered care skills "reinforcement" training (group or individual update training on communication and patient self-management support skills)

System-Centered Support:

- Patient orientation to practice policies and procedures
- Contact list assignments (staff-generated who-to-call-for-what list)
- Call response protocol and report form
- Provider-initiated call protocol
- Chart stickers (reminders for follow-up, plan, special concerns, etc.)
- Visit planner form in chart
- Patient satisfaction assessment tool
- Aggregate data report to providers on patient satisfaction (including communication skills assessments)
- Assigned patient contact person
- Appointment and waiting time improvement plan
- Lab and medical procedures descriptions in patient-friendly language
- Patient education program (stand-alone sessions; series; individual; disease-specific; communication skills; goal-setting skills; daily management skills)

Activity 6:

Role Play Practice: Action Planning

Rationale:

Action planning with patients is an important and effective patient self-management activity. It engages the patient in setting clear, measurable, and attainable goals and allows the clinician to assess the patient's sense of self-efficacy in reaching the agreed-upon goals. Working with patients on action planning involves the skills of active listening, motivational interviewing, effective communication, and collaborative management. This role play will help participants to practice and refine these skills in a supportive environment.

Materials Needed:

- Role play scenario handout
- Action-planning worksheet (HIV provider form)
- Patient Action Plan (patient form)
- Newsprint and easel
- Markers
- Masking tape

Time Needed:

45 minutes

Procedure:

1. Explain:

In this activity we will have the opportunity to try out some of the materials and methods of supporting patients in their self management that we have suggested and discussed in the last activity.

We will focus on action-planning. Action-planning is one of the most often used and most effective tactics used to support patient self-management. It has been used effectively with patients with diabetes, heart disease, asthma, arthritis, and other chronic diseases. It is something that comes naturally to some people and something that needs to be learned by other people.

Through action-planning, you and the patient work together to help the patient identify a problem that concerns them, set an achievable goal, develop a strategy with specific action steps to achieve the goal, and identify resources that might help the patient reach their goal.

2. Ask if any of the participants have had experience in action-planning with their patients. What have been some positive experiences you have had? What are some ways to make action-planning most effective? Write the suggestions on a newsprint sheet.

3. You may ask the participants to list the steps of action-planning that they use in addressing problems in their own lives. Write these on a newsprint sheet. The steps will most likely include:

•   Identify the problem

•   Set a goal

•   Suggest some possible solutions

•   Select an action that you are willing to try

•   Identify what you will do when

•   Give it a chance to work

•   Evaluate how it works and revise goal or actions steps, if necessary

4. Hand out the "Action-Planning Worksheet" and the "Getting to 7" worksheet and review them with the participants. These are suggested forms to use as a guide to action-planning with patients. They can be used as is or modified to meet individual needs and with experience. They contain some suggested questions that can start the conversation. [Please refer to the Note to Facilitators at the end of this activity for more information on the use of the "Action-Planning Worksheet" and the "Getting to 7" worksheet.]

Explain that they will practice action-planning in a role play. The role play picks up with the case of Zeke again and they will work in pairs or triads in the role play. One person will play Zeke and the other will be his HIV care provider. A third person may be the observer, not participating in the role play.

5. Explain that they will have about 10 minutes for the role play and that they should stay in their roles for the whole time. If appropriate, you may ask them to form groups of three for the role play, so that one person is an observer and has no active role. This may help in de-briefing and discussion after the role play.

6. Hand out the role play scenario. Ask them to form groups of 2 or 3, and agree upon their roles. Ask them to read the role play scenario, think for a moment about their role, and then begin the role play. Tell them that you will let them know when the time has elapsed.

7. When the 10 minutes have elapsed, ask them to stop the role play and to come back together as a group.

8. Ask them to describe what it was like to play the role of Zeke, the patient. You might ask, "How did it feel to be in the role of the patient?" "What was the most helpful thing that the HIV care provider did?" or "What do you think Zeke will do after he leaves the office?" Ask several participants to share their experience with the group.

9. Next ask them to describe the experience of the HIV care provider. "What did you feel went well in this role play?" or "What was the most difficult thing to do?" Ask several participants to share their answers with the group.

10. If there was an observer in the group, ask the observers to describe the interaction between the care provider and the patient. Have them answer the question: "Did the action-planning session work?"

11. Ask the group (care provider and patient roles) what they felt that they would do differently the next time.

12. If time permits, you might consider asking the participants to switch the roles and do the role play again. If so, repeat the de-briefing and discussion after the second role play.

13. In conclusion, ask the group what was the most important thing they learned from this activity.

Facilitator's Note

Action-Planning Worksheet

This worksheet has been developed for providers to use in helping patients to identify and address concerns that affect their health and wellness. Participants may already have a process that they use to accomplish this task. The worksheet was created to include the essential steps in action planning. There may be other forms that have been used successfully and participants may describe them.

It is suggested that the participants playing the role of the provider review the form and then try to use it during the role play, asking the questions and writing down the responses given by the participant playing the role of the patient. For each step in the action planning process, there are some suggested questions that the provider may ask to begin the conversation. Feel free to use alternative questions which address the same issue and in which the participants feel confident.

"Getting to 7" Worksheet

This worksheet can be used by the provider to help the patient to identify a goal that they truly feel they can accomplish. It is a visual measure of patient self-efficacy. Work with the patient to state a goal in action terms and write the goal on the line provided. Then ask the patient to circle the number that best reflects their prediction of success in reaching that goal. If they circle a number below 7 it is not likely that the goal will be reached and it signals to the provider that the patient doesn't feel very confident they will be able to accomplish the goal.

The goal should be restated, (scaled down a bit), to make it more accomplishable. Perhaps decrease the size of the task or increase the amount of time needed. For example, how many times per week is it likely that the patient will really be able to walk a mile after dinner?

Write the more realistic goal on the next line and then ask the patient to circle the number one more time. Continue the exercise until a goal is described that has at least a 70% chance of being accomplished.

Action Plan Role Play

HIV Care Provider Role:

At his last visit, one month ago, Zeke was given a prescription for an antiretroviral therapy regimen consisting of two pills twice a day.

In todays visit a review of his lab results indicate that he has gained some control over his HIV infection; his viral load is still detectable and his CD4+ cell count has improved somewhat. In his physical exam you see that his blood pressure remains elevated, his weight is unchanged, and his blood lipid profile is out of the normal range. You are concerned with Zeke's management of his health.

In a conversation you had with Zeke some time ago, when you asked him about the things he was most concerned with, he responded that taking care of his developmentally disabled son was his primary concern, particularly since he found out that he had HIV.

Zeke seems to be in a relatively good mood. He shows up for his appointment with his bag full of booklets and brochures about HIV and AIDS. Nevertheless, he does not look well and admits that he has not been taking good care of himself. You would like to discuss helping Zeke make a plan of action to address his health problems.

You begin the conversation.

Zeke's Role:

At your last visit to the provider, you were given a prescription for HIV medication to take. You filled the prescription and have taken most of the pills as you were told. You also have to take your medications for your blood pressure and cholesterol. It is not easy to remember to take everything. Taking all of the medications everyday reminds you that you have so many health problems to deal with and it sometimes makes you feel sad and a little scared.

Your son has been placed in a special school program that has begun to help with his behavior problems but you have had to adjust your work schedule to be home for him when he is not in school.

You are coming to your practitioner for a follow-up visit. You are unsure of how well the new medications are working. You like the practitioner and want him/her to like you.

Observer's Role:

You have no active part in this role play. Your responsibility is to objectively observe the interaction between the care provider and Zeke. You should be able to describe what happened and what you think made the interaction a positive experience as well as what might not have worked so well. What do you think will happen with Zeke after he leaves the doctor's office?

Action Planning Worksheet

Patient Name:_____   Provider Name:_____

Assess patient's primary concern or problem:

(e.g., "What is your greatest concern now?" "What one thing would you most like to change?")

_____

Explore patient's feelings about the problem:

("What do you think makes this so hard for you?" "How will you feel if things don't change?")

_____

Identify patient's goals:

("How would you like the situation to change?" "What one thing do you want to change?")

_____

Brainstorm solution ideas:

("What do you think might work or help you to reach that goal?" "How do you think you might solve this problem?" "What have you tried in the past?" "How might I or someone else help you to do this?")

_____

Choose a solution and action steps to try:

("What do you think you could do?" "When would you do it?" How often do you think you could do that?" "What will you do to get started?")

_____

Estimate self-efficacy [Use the "Getting to 7" Scale]:

("Does this sound like something you can do?" "Are you sure this is something you want to do?" "On a scale of 1 to 10 how likely is it that you will actually be able to do that?")

_____

Making Sure HIV Patient Self-Management Works:
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Getting to 7

Use the scales below to estimate how likely it is that you will be able to accomplish the goal you have set.

Write the goal on the line above the first 1-to-10 scale. The goal should be: "What you will do by when." Then circle the number, on a scale of 1 to 10, which shows how likely you think it is that you will actually accomplish the goal.

Goal:_____

Not Likely	1	2	3	4	5	6	7	8	9	10	Very Likely

If you selected a number below 7, try to revise your goal to make it more realistically fit what you think you can actually accomplish.

Revised Goal:_____

Not Likely	1	2	3	4	5	6	7	8	9	10	Very Likely

Revised Goal:_____

Not Likely	1	2	3	4	5	6	7	8	9	10	Very Likely

Revised Goal:_____

Not Likely	1	2	3	4	5	6	7	8	9	10	Very Likely

Patient Action Plan

Patient Name:_____   Date:_____

Most important problem or concern: _____

Why is this so difficult? _____

How will you feel if things don't change? _____

What have you done in the past to try to solve the problem or to change the situation?

_____

How would you like the situation to be different? What is your goal to accomplish?

_____

What do you think could be done to change the situation?

_____

Goal and Action Steps:

What are you going to do? _____

When are you going to do it? _____

How are you going to do it? _____

Who would you ask to help you? _____

What do you need to get started? _____

What will you do, or how will you feel, when you reach your goal? _____

_____

Activity 7:

Self-Management Program Action-Planning

Rationale:

Introducing or developing patient self-management programs in the clinical care setting may encounter some barriers. Some may be institutional, others may be personal, and still others may be financial or logistical. Effective programs often begin with small steps and with a small group of dedicated individuals. In some cases, individual initiatives and experiences serve as models to others. In this activity, participants will brainstorm action planning to assist them in initiating or developing a patient self-management program in their clinics. Participants will first work individually to develop an action plan for patient self-management programming in their clinics. Then in small group work, participants will support one another in further refining the action plans.

Materials Needed:

- Self-management program action-planning form
- Newsprint and easel
- Markers
- Masking tape
- Post-it notes or index cards

Time Needed:

30 minutes

Procedure:

In the last activity you practiced patient self-management action planning on an individual basis in a hypothetical role play.

In this activity you will apply the same principles of action planning to initiating or developing patient self-management support programs in your own clinical setting.

You all probably have very different experiences with patient self-management programs in your practices.

The goal of this activity is to identify and address your most important concerns about either initiating or developing patient self-management programs in your practices. These goals should not be hypothetical.

1. Explain:
2. Ask the participants to identify the problem about patient self-management in their practices that is of most concern to them. Ask them to write a concern on a card and hand the cards to you. Read the concerns and write the key issue or phrase on a newsprint sheet. All participants need not contribute to the list. Using cards may give some of those who are reluctant an easier way to participate.

3. Explain that in dealing with the concerns they have offered we will work first individually on an action plan and then in small groups to brainstorm action planning on one or two of their cases.

4. Hand out the "Self-Management Program Action-Planning" form to each participant.

5. Review the form with the group. They will see that it is similar in many respects to the action planning form used in helping patients to plan for specific behavior change.

6. Having identified some problems or concerns that the group has concerning the development of a patient self-management program in their clinic setting, ask the participants to identify one problem or concern and to write an action plan individually for themselves to address that concern. Encourage them to select a real problem that they would like to work on.

7. Ask them each to write their concern or problem on the action-planning form.

8. Tell them that they will have 5-10 minutes to work on their action plan, and that after the action plans have been finished they will form their small groups for discussion.

9. Ask them to begin work individually on their action plans.

10. When you see that all have finished work on their plans, or when 10 minutes have elapsed, ask them to form small groups of 3-5 individuals.

11. When the groups have been formed, ask them to select one action plan volunteered by a member of their group to review. [Alternatively, if there are not enough action plans volunteered in the small groups, you may ask for one volunteer to read their action plan to the whole group for general discussion.]

12. Tell them that after the action plan is read to the group they should discuss the plan, first answering questions for clarification and then addressing the specific components identified by the writer of the plan that need refinement.

13. Tell them that the goal of the discussion is to help the writer to come up with a plan that he or she can work with. Keep in mind that action plans have to fit both the problem and the person.

14. Tell them that they will have 10 minutes for the discussion.

15. When 10 minutes have elapsed, ask them to come back together as a group. Ask for one or two volunteers to read their action plan to the whole group, identify what they like best about the plan and also what they feel they may need further help with in the plan.

16. When finished, thank the volunteers for their participation. Ask the group what they have learned as a result of this activity.

17. Wish them well in the implementation of their action plans, and encourage them to continue to work with one another on further aspects of their patient self-management program development.

18. Tell them that this was the last activity in the workshop and that in next few minutes they will evaluate the training.

Self-Management Program Action Plan

Program Name:_____   Date:_____

Most important problem or concern: _____

Why is this so difficult? _____

How will you feel if things don't change? _____

What have you done in the past to try to solve the problem or to change the situation?

_____

How would you like the situation to be different? What is your goal to accomplish?

_____

What do you think could be done to change the situation?

_____

Goal and Action Steps:

What are you going to do? _____

When are you going to do it? _____

How are you going to do it? _____

Who would you ask to help you? _____

What do you need to get started? _____

What will you do, or how will you feel, when you reach your goal? _____

_____

Activity 8:

Workshop Evaluation

Rationale:

The workshop evaluation has two purposes: it is designed to assess the value of the workshop to the participants for the purpose of improving the quality of the training and its other purpose is to help the participants to review and assess what they have learned in the training.

Materials Needed:

- Workshop evaluation form
- Newsprint and easel
- Markers
- Masking tape

Time Needed:

10 minutes

Procedure:

1. Ask the participants to share some of their reactions to the workshop such as: "What did you find most valuable to you about the workshop?" "What did you find to be least valuable?" "In what ways do you think the training could be made more valuable?" You may write the key points made by the participants about the workshop on a newsprint sheet.
2. When finished, thank the participants for their work and contribution to the workshop.
3. Explain that there is a workshop evaluation you would them to complete.
4. Hand out the anonymous workshop evaluation form.
6. Ask the participants to fill out the evaluation form and to hand it back to you when it is completed.

Making Sure HIV Patient Self-Management Works

Workshop Evaluation Form

Please complete the following workshop evaluation questions by circling your responses. Your input will help us to improve the workshop and to identify possible needs for future workhops. Thank you.

	POOR	FAIR	GOOD	EXCELLENT
1) How do you rate today's workshop?	1	2	3	4
2) How do you rate the quality of the trainer?	1	2	3	4
3) What is the value of the information covered?	1	2	3	4
4) Was the workshop interactive and engaging?	1	2	3	4
5) What is the likelihood you would refer others to the workshop?	1	2	3	4

6) Which activity, if any, did you find LEAST valuable?

_____

7) Which activity, if any, did you find most valuable?

_____

8) What, briefly, did you find to be the most valuable information or skill you learned in the workshop?

_____

9) What would you suggest we do to make this workshop more useful to your colleagues?

_____

References and Recommended Reading

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For more detailed information on these readings, please see the annotated bibliography of key self-management articles, visit our website at NationalQualityCenter.org, or order by calling 212- 417-4730.

Annotated Bibliography

Aberg J. The Changing Face of HIV Care: Common Things Really Are Common. Ann Intern Med. 2006;145(6):463–65.

"Now more than ever, HIV care is primary care. Common things are common. Developed countries are experiencing an epidemic of conditions: obesity, CHD, diabetes, and lung cancer. Physicians everywhere must remember that most of their HIV-infected patients will survive to develop the diseases that plague the rest of us."

This editorial relates to an original research study published in the same issue of the journal (Sackoff et al. Ann Intern Med. 2006) detailing the demographics and causes of death among people with HIV in New York City between 1999 and 2004. The editorial demonstrates that the percentage of deaths due to non-HIV related causes in that population has increased. They reported that 76% of deaths due to non-HIV-related causes were attributed to substance abuse, cardiovascular disease, and age-appropriate malignancies. According to Aberg, these data support the general conclusion that HIV infection is a chronic disease and that as people with HIV live longer they develop the similar chronic co-morbid conditions that affect the non-HIV population.

- The implication of this editorial is that, given the transition of HIV to a long-term, chronic disease, there is a need to support the development of self-management skills among patients living with HIV, not only to manage their disease, but also emphasize life-long health skills. The Chronic Care Model has been applied in the context of many other chronic illnesses and therefore provides a framework for HIV care.

Anderson B and Funnell M. The Art of Empowerment: Stories and Strategies for Diabetes Educators. American Diabetes Association. 2000.

"Most patients have the capacity to develop the skills and attitudes necessary to make decisions appropriate to their lives...We feel it is our responsibility to provide our patients with the resources to achieve their own...care goals."

The philosophy and practical skills of patient empowerment are presented in this short book published by the American Diabetes Association. Anderson and Funnel pioneered the strategies and tactics of patient empowerment that form the basis of many patient self-management models. While this book is focused on methods of empowering patients with diabetes, it applies equally well to methods of working with all patients with chronic disease. Characteristic of the tone of the book is the following: "The empowerment philosophy has freed us from the responsibility of attempting to solve all of our patients' problems. It allows us to enter into a dialogue with them during which solutions to problems emerge naturally from an exploration of issues in a relationship based on trust and respect."

- The text is filled with case studies of patients with diabetes in which the process of working in partnership with patients is demonstrated by example. Each example is supported by practical insights into how to work with patients in solving complex self-management problems.

Anderson R. Patient Empowerment and the Traditional Medical Model: A Case of Irreconcilable Differences? Diabetes Care. 1995;18(3):412-415.

"We are not suggesting that physicians and other health care professionals give up being in charge of the treatment of diabetes. Rather, we are suggesting that they give up the illusion that they are in charge of the day-to-day management of diabetes."

The patient empowerment approach is based upon the belief that the traditional medical model is inappropriate and unworkable in the management of chronic illness. According to Anderson, patients carry out 95% or more of the daily self-care of diabetes. Such care is not just about taking medications; it is about virtually every aspect of the patient's life.

- The focus of this analysis is the author's experience with patients with diabetes. However, concepts are equally valid for any chronic disease, including HIV.

Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient Self-Management of Chronic Disease in Primary Care. JAMA. 2002;288(19):2469-2475.

" 'What is your most important problem?' Never having been asked that question, Ricky's instinct was to say, 'weigh too much, cholesterol too high, sugar too high, and blood pressure too high.' Instead, he began to describe the trouble he had last night preventing his son from throwing his dinner on the floor and daily battles he faced caring for him. It became clear that Dr. Fine's perception of Ricky's main problem was quite different from Ricky's perception."

This is a comprehensive review of evidence supporting the importance and benefits of patient self-management support in the care of patients with chronic illnesses. Studies in which self-management education, one type of self-management support, has been tested in clinical trials involving patients with chronic diseases are described. Data are presented which indicates that self-management education can improve clinical outcomes, improve patient self-efficacy, and reduce costs. This article is the fourth in the series "Innovations in Primary Care" which describes the Chronic Care Model and the role of patient self-management in that model.

- The case study involving the brothers, Ralph and Ricky, serves as the basis for understanding the need for physicians to engage patients with chronic illness in collaborative goal-setting and action-planning as the central feature of self-management support.

Coleman M. and Newton K. Supporting Self-Management in Patients with Chronic Illness. Am Fam Physician. 2005;72;8:1503-10.

"Increasing evidence shows that self-management support reduces hospitalizations, emergency department use, and overall managed care costs."

Patient self-management support provided by physicians in family practice for their patients with chronic illness is described and practical interventions that can be integrated into routine office practices are suggested. "Physicians who want to provide increased support of their patients' self-management are advised to address three areas: structuring patient-physician interactions to include goal-setting and problem-solving strategies, making office system changes, and providing self-management education by linking patients to community self-management programs."

- Practical tools such as sample provocative questions for use in planned visits, a patient's personal action-planning form, and steps to support self-management are provided.

Gifford A, Laurent D, Gonzales V, Chesney M, Lorig K. Pilot Randomized Trial of Education to Improve Self-Management Skills of Men with Symptomatic HIV/AIDS. J Acquir Immune Defic Syndr Hum Retroviral. 1998;18136-144.

"Health education emphasizing self-management skills for HIV/AIDS patients can be implemented and evaluated and was accepted by patients, peer leaders, and health care providers. Whether this educational program can lead to prolonged improvement in HIV symptoms and behaviors can be adequately addressed only by a larger trial of longer duration."

This study was a pilot test of a seven-session group educational intervention for HIV/AIDS patients based upon the model chronic disease self-management curriculum developed at Stanford University. Seventy-one men with symptomatic HIV infection were randomly assigned to participate in either an educational intervention or a usual-care control group. The results showed that symptom severity index decreased in the education session group and increased in the control group. Self-efficacy improved in the educational group and decreased in the control group. Other secondary outcome measures (pain fatigue, psychosocial symptoms, changes in stress/relaxation exercises, and HIV/AIDS knowledge were not significantly different in the two groups.

- There has been no follow-up of this pilot study with a larger long-term study reported to date.
- A training manual to accompany the patient education sessions used in this study has been published. It is *Living Well with HIV and AIDS* by Gifford, Lorig, Laurent, and Gonzalez, published by Bull Publishing Company.

Guevarra J, Wolf F, Grum C, Clark N. Effects of Educational Interventions for Self-Management of Asthma in Children and Adolescents: Systematic review and Meta-analysis. Br Med J. 2003;326:1308–1314.

"Educational programmes for the self-management of asthma in children and adolescents improve lung function and feelings of self control, reduce absenteeism from school, number of days with restricted activity, number of visits to an emergency department, and possibly number of disturbed nights. Educational programmes should be considered a part of the routine care of young people with asthma."

Patient self-management programs for adults with asthma, including self-monitoring of symptoms and the development of an asthma action plan have been shown to be effective in reducing morbitity and the use of healthcare resources. This database meta-analysis studied the controlled clinical trials data evaluating the use of self-management programs for children and adolescents with asthma. The authors found that patient self-management education and other self-management interventions were effective in improving clinical outcome and reducing the utilization of health care resources in this patient population.

- Self-management programs in the care of patients with chronic illness such as asthma can serve as both models for the development of programs for patients with HIV/AIDS, and in establishing the theoretical support and "proof" of efficacy that may help get buy-in for the development of new programs.

Health Resources and Services Administration. HRSA CARE ACTION: Self-Management and the Chronic Care Model. January 2006.

"The incorporation of self-management education into CARE Act activities could empower patients to take a more proactive role in managing their illness and improving their quality of life. Moreover, HIV/AIDS self-management programs have the potential to serve as the foundation for a more effective and satisfying patient-provider partnership, to enhance the psychosocial and physical health of PLWHA, and reduce the resources needed for case management."

As people with HIV/AIDS move into medical care, they are similar in many respects to patients with other chronic illnesses for whom self-management has proven to be effective in improving clinical outcomes, quality of life, self-efficacy and reducing the utilization of health care resources. Some differences, though, are unique to HIV/AIDS patients: adherence to antiretroviral medications is complex, daily self-monitoring is difficult and stigma is pervasive and strong. Despite these differences, studies among PLWHA have shown that self-management education and other interventions have the potential to improve the health and self-efficacy of patients and to improve the patient-physician relationship.

- HRSA supports the development and implementation of patient self-management initiatives for PLWHA in CARE Act-funded programs.

Lorig K, Sobel D, Ritter P, Laurent D, Hobbs, M. Effect of a Self-Management Program on Patients with Chronic Disease. Eff Clin Pract. 2001;4:256-262.

"We found that patient use of CDSMP was associated with better outcomes in all study domains small but statistically significant improvements in health status, health behavior, and self-efficacy and less use of the ED."

In this community-based study, 489 patients with various chronic diseases who were being treated in Kaiser Permanente Hospitals attended a peer-led, seven-session, small group, self-management education course (Chronic Disease Self-Management Program; CDSMP). After 1 year, patients participating in the course were found to have improved health behaviors, self-efficacy, health status, and had fewer visits to the emergency department compared with baseline data.

- The CDSMP is the model educational program for patient self-management education. It combines peer-led disease-specific education with training in communication skills, decision-making, action-planning, and health-promotion techniques.

Marelich W and Murphy D. Effects of Empowerment Among HIV-Positive Women on the Patient-Provider Relationship. AIDS Care. 2003;15(4):175-181.

"Findings from this study suggest that HIV-positive women who exhibit empowered behaviours received more information from their providers and reported better patient-provider communications. Thus, it is our recommendation that providers help cultivate such empowered behaviours in their HIV-positive female patients, and move toward developing treatment partnerships with their patients."

Fifty women with HIV who were enrolled in a longitudinal cohort of HIV-positive adult women participated in this study of the relationship between patient-reported attitudes and behaviors related to their health care and their sense of empowerment. Those who were found to have better decision-making, communication, and self-management skills were found to have better relationships with their providers and to receive more health-related information from their providers. Providers are advised to assess their patient's "will and skills" to take a more active role in their treatment and to assist patients in developing those skills.

- The patient-provider relationship is improved when female patients with HIV/AIDS feel empowered in the management of their health and health care.

Rukeyser J, Steinbock C, Agins, B. Self-Management in Chronic Disease. JAMA. 2003;289(12):1508-9.

"Self-management is an essential part of chronic disease care, and it includes both patient and provider responsibilities. It is important that our thinking not be limited to its structured patient-education component alone. Interventions that combine various forms of patient education with physician facilitation of collaborative goal-setting are more likely to be successful."

In response to the article by Bodenheimer et al describing the important role of patient self-management education (Bodenheimer et al. JAMA. 2002;288(19):2469-2475), this letter to the editor calls for a broadened view of patient self-management, beyond the structured, time-limited educational intervention, to encompass both health care system and provider-based supports for patient self-management.

- The case study presented in Bodenheimer et al 2002 provides a basis for understanding differences among patients in their approach to managing their health and exploring the role of health care providers in supporting patients in self-management skills development.

Von Korff M, Gruman J, Schaefer J, Curry S, Wagner E. Collaborative Management of Chronic Illness. Ann Intern Med. 1997;127(12);1097-1102.

"Key principles of [social learning and self-regulation] theories include the ideas that 1) illness management skills are learned and behavior is self-directed; 2) motivation and self-confidence (or self-efficacy) in management of illness are important determinants of patients' performance of self-care; 3) the social environment of the family, workplace, and health care system can support or impede self-care; and 4) monitoring and responding to changes in disease state, symptoms, emotions, and functioning improves adaptation to illness."

In the collaborative model, health care providers can use behavioral techniques to improve patient self-management. These techniques include: goal-setting; assessing a patient's readiness for self-management; using action-planning to break complex or difficult tasks into small manageable steps; giving personalized feedback; and enlisting social support, among others. According to the authors, even low-intensity behavioral interventions can be effective in learning or changing patient health behaviors. Collaborative management begins when patients and care providers define problems clearly, using terms that they both understand and agree upon. Even the smallest of steps, such as asking a patient to identify the biggest problems faced in managing illness, may provide the basis for improved collaboration. Patients' self-management abilities can be enhanced by services that teach skills needed to carry out medical regimens, change health behaviors, and provide them with emotional support.

The key elements of collaborative care include: 1) Collaborative definition of problems from the perspective of both the clinician and the patient; 2) Goal-setting and action planning in the context of the patient's readiness and skills; 3) A continuum of self-management training and support services; and 4) Active, continued follow-up, reinforcement, and re-assessment.

• Training for health care clinicians in patient self-management support should include practice in each of the key elements of collaborative care.

Warsi A, Wang P, LaValley M, Avorn J, Solomon D. Self-Management Education Programs in Chronic Disease. Arch Inter Med. 2004;164:1641–1649.

"While self-management education programs are conceptually appealing, and while there has been growing interest in them as a means of empowering patients, improving outcomes, and reducing health care costs, the findings of this review suggest that not all self-management education programs for all diseases are effective."

Seventy-one (71) trials of self-management education across several chronic disease states were analyzed for consistency of methodology and data on clinical outcomes. Self-management education programs resulted in small to moderate effects for selected chronic diseases. The findings demonstrated a lack of consistency in study methodology as well as variability in achieving stated clinical outcomes. Those interventions which included a face-to-face educational component were found to more effective across disease states. In addition, the authors concluded that self-management education programs might be more effective in specific patient subgroups.

- Patient self-management programs which tailor educational content and methodology to individual patients and which are integrated into medical care may prove to me more effective than structured self-management education courses, for which only specific patient subgroups may be ready.