

Skills for Chronic Disease Management

Materials in Preparation for Session One

Please send the following materials and readings out to participants at least **two weeks** before this study circle begins, and ask participants to read these materials before attending Session One.

These materials will provide some context for this Health Literacy Study Circle+, help to prepare participants for the overall experience, and serve as the basis for discussion in Session One.

Materials/Handouts

1. Welcome Letter to Participants (A template for you to customize with appropriate information for your study circle participants)
2. Participant Expectations *
3. Participant Definition of Health Literacy

Background Readings (10)

1. Skills for Chronic Disease Management: Goals and Objectives
2. Development of the Guides to the Health Literacy Study Circles+
3. A Letter from Rima Rudd -- Principal Investigator, Health Literacy Studies
4. A Letter to Adult Education Practitioners from Lee Hewitt -- an ESOL Teacher and Health Curriculum Developer
5. A Letter from Charlotte Nath -- Nurse and Educator
6. Guiding Questions for *A Maturing Partnership* by Rima E. Rudd
7. *A Maturing Partnership* by Rima E. Rudd
8. Background Information and Useful Definitions for Chronic Disease Management
9. Shared Goals but Different Roles in Health Literacy
10. Additional Resources (For Your Information)

List of Participants

If you do not have time to create a list of participants with contact information before Session One, please bring the following form (List of Participants) to Session One and ask people to sign it. Then make copies for everyone so people can contact each other between sessions.

* Should be completed by participants and returned to you before Session One begins.

Health Literacy Study Circle+
Skills for Chronic Disease Management
Dates: _____

List of Participants

Name	Program Information	Phone Number and E-mail Address
Facilitator:		

Welcome Letter to Participants (A template for you to customize)

Dear Participant:

Welcome to the Health Literacy Study Circle+ (plus) on Skills for Chronic Disease Management. This program will be an exciting, enriching, and challenging experience that I truly hope you will enjoy.

In preparation for your participation in the Study Circle+, I would like to point out the dates, times and locations of the five sessions:

	Date	Time	Location
Session One			
Session Two			
Session Three			
Session Four			
Session Five			

Given the highly interactive nature of this study circle, and the interconnectedness of its sessions, it is essential that you attend all sessions.

Please notify me immediately if you cannot attend one of these sessions.

The Study Circle+ will be an intense, hands-on learning experience. Study circles are generally designed to provide an opportunity for individuals to reflect in-depth about a topic and exchange ideas. In this Study Circle+, you will do that and more. You will:

- Learn about recent health literacy research
- Think about ways of bringing health literacy skill development to your classrooms and students
- Identify your students' needs and interests related to health literacy
- Try out health literacy lessons with your students and create your own lessons and units

The Study Circle+ sessions themselves will provide a venue for preparing for and reflecting on your new teaching experiences. Come prepared to share your ideas, learn from others, and “roll up your sleeves” as you engage in activities that may challenge your current thinking and practice.

This packet includes the following materials, which were designed to help you prepare for Session One. Please read them and bring them with you to Session One.

Handouts

1. Participant Expectations (Please complete and return this sheet to the facilitator before Session One.)
2. Participant Definition of Health Literacy

Background Readings

1. Skills for Chronic Disease Management: Goals and Objectives
2. Development of the Guides to the Health Literacy Study Circles+
3. A Letter from Rima Rudd -- Principal Investigator, Health Literacy Studies
4. A Letter to Adult Education Practitioners from Lee Hewitt -- an ESOL Teacher and Health Curriculum Developer
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6. Guiding Questions for *A Maturing Partnership* by Rima E. Rudd
7. *A Maturing Partnership* by Rima E. Rudd
8. Background Information and Useful Definitions for Chronic Disease Management
9. Shared Goals but Different Roles in Health Literacy
10. Additional Resources

Before Session One begins

- Read the materials included in this packet. They will serve as the basis for discussions in this study circle.
- Complete and return the Participant Expectations sheet to me, using the enclosed self-addressed envelope.
- Complete the Participant Definition of Health Literacy and bring it with you to Session One.

Please contact me if you are missing any of the materials listed above or if you have any questions about this study circle. I look forward to meeting with you at our first session on _____ (date).

Sincerely,

The Facilitator (Your Name)
Mailing Address
Phone number
Email address

Participant Expectations

~ Please complete and mail this back to the facilitator prior to Session One ~

List three things about health literacy and/or health literacy skill development that you are interested in learning.

1)

2)

3)

Participant Definition of Health Literacy

~ Please answer this question and bring this sheet to Session One ~

What is your definition of “health literacy?”

Skills for Chronic Disease Management: Goals and Objectives

Study Circle+ Goals

The overall goal of the Health Literacy Study Circle+ is to build the capacity of adult education instructors to incorporate health literacy skills into their curriculum and instruction.

The goal for the Chronic Disease Management Study Circle+ is to prepare participants to help their students develop basic skills needed for managing a chronic disease. These skills include filling out forms, managing medications, following verbal and written directions, talking with doctors, and using tools to measure medications and monitor their conditions.

Study Circle+ Objectives

Participants in the Chronic Disease Management (CDM) Study Circle+ will:

1. Develop a shared definition of “health literacy.”
2. Identify the activities people engage in when they are trying to manage a chronic disease.
3. Identify literacy related barriers and issues faced by people who are managing a chronic disease.
4. Identify health literacy skills needed to accomplish the many tasks involved in managing a chronic disease.
5. Teach, modify, and critique sample lessons designed to build students’ literacy and numeracy skills related to chronic disease management.
6. Create and pilot a lesson based on students’ needs.
7. Outline a sequence of lessons for a health literacy unit and draft an evaluation plan.
8. Develop strategies to incorporate health literacy skills into classroom activities.

Development of the Guides to the Health Literacy Study Circles⁺

As the Health and Adult Literacy and Learning (HALL) team assembled to develop the Health Literacy Study Circles⁺ guides, we listed the multiple health activities adults engage in when they are at home, at work, in the community, in health care settings, and even in the voting booth.

Health Activities

Health activities are part of everyday life. We maintain and safeguard our health and that of loved ones, fellow workers, and neighbors. We make decisions about food purchases and preparation. We buy and use home products that include food and cleaning chemicals, as well as appliances and equipment. We are concerned with the quality of our houses or apartments and community. We pay attention to work processes and chemicals. We take action when we are well to prevent illness and disease. We seek care when we do not feel well and make decisions about when we, or those we love, need to talk with a doctor, nurse, dentist, or pharmacist. We have to sift through papers and fill out forms when we apply for insurance or benefits. We need to be aware of and advocate for our rights.

The HALL team organized the many health-related tasks of everyday life into the following five groups of activities:

1. **Health Promotion:** Those actions we do to stay healthy. Included are everyday decisions about eating, exercise, and rest.
2. **Health Protection:** Those actions we do to protect our health and that of our community. Included are rules and regulations about product labels, clean air and water, and safe food and products.
3. **Disease Prevention:** Those actions we do to prevent disease and to detect disease at very early stages. Included are actions such as use of sunscreen or participation in a screening test.
4. **Health Care and Maintenance:** Those actions we do when we seek advice or help from health care professionals, whether we are well, ill, in recovery, or when we need to manage a chronic disease. Included are well baby visits, checkups, and advice and care when we do not feel well.
5. **Navigation:** Those actions we do to obtain health coverage and care and to make our way through the hallways of health institutions, agencies, and service providers. Those actions include making decisions about benefit packages, giving informed consent for procedures, and completing the many forms needed to obtain coverage and care.

(Table 1 offers a brief description of each of these groups of activities with examples of materials we use and tasks we undertake.

Table 1: Health Activities, Focus, Materials, and Tasks

Health Activities	Focus	Materials Adults are Expected to Use	Tasks Adults are Expected to Accomplish
Health Promotion	Enhance and maintain health	Labels on cans of food or recipes Articles in newspapers and magazines Charts and graphs such as the Body Mass Index Health education booklets (such as well baby care)	Purchase food Prepare a dish from a recipe Plan exercise Maintain healthy habits (re.: nutrition, sleep, exercise) Take care of everyday health (self and family members)
Health Protection	Safeguard health of individuals and communities	Newspaper chart about air quality Water report in the mail Health and safety posting at work Label on a cleaning product	Decide among product options Use products safely Vote on community issues Avoid harmful exposures
Disease Prevention	Take preventive measures and engage in screening and early detection	Postings for inoculations and screening Letters reporting test results Articles in newspapers and magazines Charts and graphs	Take preventive action Determine risk Engage in screening or diagnostic tests Follow-up
Health Care & Maintenance	Seek care and form a partnership with a doctor, dentist, or nurse	Health history forms Labels on medicine Health education booklets Directions for using a tool such as a peak flow meter	Seek professional care when needed Describe symptoms Follow directions Measure symptoms Manage a chronic disease (follow regimen, monitor symptoms, adjust regimen as needed, seek care as appropriate)
Navigation	Access health services, and get coverage and benefits	Application forms Statements of rights and responsibilities Informed consent forms Benefit packages	Locate facilities Apply for benefits Fill out forms Offer informed consent

Health Materials, Tasks, and Skills

Many ordinary health tasks require us to use specific materials. Parents look at the label on the package to find out how much medicine to give children. Elders fill out Medicare forms to obtain needed services. Consumers read product labels as they mull over which products will best serve their needs. Patients are given discharge instructions when they leave the hospital to return home and minister to their own needs.

Sadly, over 300 articles in public health and medical journals indicate that health materials are often complex, contain scientific terms instead of everyday language, and are written at reading levels beyond the level of difficulty found in high school texts. Indeed, studies indicate a mismatch between the demands of health materials and the average reading skills of U.S. adults. Many health materials – the tools that are supposed to help us by providing information, directions, rights and responsibilities – do not serve this purpose.

Being able to read health materials and carry out health care tasks requires background information that is often not provided nor made explicit. For example, consider the label on food products. Does everyone know the names of the types and forms of sugar? Or, consider what seems to be a simple direction: *take one tablet three times a day*. The doctor, dentist, nurse, or pharmacist knows that medicine needs to be in the body throughout the day. As a result, they want the patient to take the medicine at very different times of the day so that it is distributed evenly. However, this is not stated. The patient who anticipates a very busy day and who follows directions by taking one pill at 7 am, one pill at 7:30 am, and one pill at 8 am may harm him or herself. As another example, the chart on the box of an over-the-counter medicine often requires sophisticated reading and math skills in order to determine how much medicine to take.

Those responsible for health communication need to make changes in the materials we ask adults to use. Health care professionals also need to improve their ways of explaining health care instructions so that adults are able to take care of themselves and their loved ones. At the same time, adult educators need to consider and improve the skills adults need as they engage in health related activities.

Reducing Health Disparities

As you might imagine, the full array of health-related activities, materials, tasks, and skills can be overwhelming. We chose to focus on critical issues and needs that are related to health disparities in the United States. A growing body of public health and medical literature indicates that those who are poor and those with less education are more likely to face health problems than are those with higher income and more advanced education. For example, the 1998 report from the Secretary of Health and Human Services to the President and Congress indicated that health status is related to income and education.

- Children in lower income families are less likely to receive needed health care than are children from higher income families.
- Adults under the age of 65 with low family incomes are less likely to have health insurance coverage compared to adults with higher incomes.
- Life expectancy is related to family income. People with lower family incomes tend to die at a younger age than those with higher incomes.
- Adults with low incomes are far more likely to report fair or poor health status compared with adults who have higher incomes.
- Infant mortality is more common among the children of less educated mothers than among children of more educated mothers.
- Adults with less education are more likely to die from chronic diseases, communicable diseases, and injuries than are adults with more education.*

Unfortunately, a 2002 report, *Trends in the Health of Americans*, indicated that these disparities continue to exist.**

The Role of Adult Education

Improved health literacy is one of the objectives for our country, as noted in *Healthy People 2010*, the document that offers the 10-year health goals and objectives for the nation. The Department of Health and Human Services calls for partnerships between the public health and adult literacy fields in *Communicating Health (2003)*, an action plan for the nation. In addition, the importance of these partnerships is highlighted by the National Academies of Science in the Institute of Medicine report *Health Literacy: A Prescription to End Confusion (2004)*.

During 2004, Surgeon General Carmona noted in several speeches that “health literacy is the currency for all I am trying to do to reduce health disparities in the United States.” Health literacy is of critical importance. Increasingly, health policymakers are recognizing how much they can learn from adult educators who are experts in teaching literacy skills to adults. Policy reports have highlighted the need for partnerships among professionals and practitioners in the two fields of health and adult education.

The Health Literacy Study Circles+ Series

The HALL team developed three study circles, each one focused on a set of skills of critical importance to the people coming to adult education programs. Each of the three study circles explores a group of health activities where we see health disparities and where adults with limited literacy skills may face serious barriers.

* Pamuk, Majuc, Heck, Reuben, Lochner. *Socioeconomic Status and Health Chartbook. Health, United States, 1998*. Hyattsville, MD: National Center for Health Statistics. 1998.

** Pastor, Makuc, Reuben, and Zia. Chartbook on Trends in the Health of Americans, Health, United States. 2002. Hyattsville MD: National Center for Health Statistics. 2002.

- ❖ **Skills for Health Care Access and Navigation:** This study circle was developed because adults with less income and less education do not have the same access to health care as do adults with more income and education. Those with limited literacy skills face cumbersome signs, vocabulary, processes, and forms as they try to access care and make their way through various health care settings. Stronger skills in vocabulary, advocacy, and in completing forms, for example, can help adult learners gain access to coverage, care, and services and help them better understand their rights and responsibilities.
- ❖ **Skills for Chronic Disease Management:** This study circle was developed because adults with less education are more likely to die of a chronic disease than are adults with more education. Adults need strong skills related to using labels and documents, talking about and describing feelings and changes in one's body, and understanding and using measurement tools -- in order to manage a chronic disease such as asthma, diabetes, or hypertension.
- ❖ **Skills for Disease Prevention and Screening:** This study circle was developed because adults with less education and less income do not engage in disease prevention activities and take part in screening programs at the same rate as do those with stronger resources. Adults with limited literacy skills have difficulty with math concepts such as rates and proportions or risk and probability. Adults need strong literacy skills to grapple with consent documents and follow up reports.

The work in the study circles focuses on existing skills adult educators have and use to teach reading, writing, oral presentation, oral comprehension, and math skills – those skills needed to use health print materials, to apply basic math to health problems, and to engage in dialogue and discussion with health professionals. The focus of these study circles meets articulated goals and objectives of state education plans for ABE and ESOL instruction. At the same time, these study circle activities can help improve health literacy and the ability of adults to meet the many expectations and demands of everyday life.

We look forward to this partnership.

Rima Rudd

Rima E. Rudd, Sc. D.
Principal Investigator, Health and Literacy Studies
Harvard School of Public Health

A Letter from Rima Rudd -- Principal Investigator, Health Literacy Studies

Dear Study Circle+ Participants,

This study circle, focused on Health Literacy Skills for Chronic Disease Management was created by the Health and Adult Literacy and Learning (HALL) research team at the Harvard School of Public Health. The team consists of public health and adult education researchers and practitioners. We are part of the National Center for the Study of Adult Learning and Literacy (NCSALL). This study circle is focused on health literacy skills development. Health literacy is now on the national agenda.

The term “health literacy” is still defined in various ways. In general, the term indicates a growing recognition in the fields of public health, medicine, nursing, dentistry, and pharmacy that strong literacy skills are critical for health-related actions. Since 2003, the U.S. Surgeon General of the United States has been emphasizing the importance of health literacy and the link between literacy and health outcomes. Healthy People 2010, the nation’s ten-year statement of health goals and objectives, includes the objective to “improve health literacy.” In April 2004, the Institute of Medicine of the National Academies of Science published a committee report on this topic: *Health Literacy: a prescription to End Confusion*.

Over the past several years, various organizations have supported national and local forums, training programs, as well as films and educational materials for health researchers, practitioners, and institutional administrators to address issues related to health literacy. Many of these initiatives are designed to improve the communication skills of health professionals. Some are also focused on improving the written materials used in health care settings and the communication approaches used in community based health programs.

Of course, U.S. adults need to improve their skills as well. When literacy is limited, words can get in the way. Adults with limited literacy skills may take a more passive role in their encounters with health professionals. They may lose their way, lose their coverage, lose their rights, or endanger their health. The adult basic education and ESOL systems are wonderful vehicles for promoting such skill development. Note the emphasis on skills. Those of us at HALL feel it is inappropriate to ask adult education teachers to teach health content. Instead, we hope they will use their expertise as adult educators to integrate health literacy skills into their programs.

Health literacy skills refer to those reading, writing, listening, speaking, and math skills adults need in order to use health materials and accomplish health-related tasks. Adults in today’s society need to interact with social service agencies and find their way in health and dental care settings. They are expected to form partnerships with health providers and manage their own health needs

and the tasks involved in living with a chronic disease. They are also expected to learn health information and take action to prevent disease and to detect disease at early stages. These and other tasks can be daunting.

Many health professionals talk about the large numbers of people in care who do not follow their regimen. These patients might not, for example, follow dietary guidelines or may not take their medicine as instructed. Few professionals, however, have paid attention to the demands of the activities and to the skills needed. For example, following dietary guidelines may involve the following activities:

- Reading labels on food items to check salt or sugar content
- Reading and following directions for new ways to cook
- Understanding how professionals group foods and what the terms mean (e.g. carbohydrates, protein)
- Understanding and measuring correct “portion size”
- Substituting appropriate ethnic foods for the more generic lists found in most handouts

Thus “following guidelines” demands very sophisticated reading and measurement skills. Similarly, “taking medicine” for a chronic disease is not a simple task. A person is expected to read and understand medicine labels, to differentiate among several different pills, to count dosage, and to use a clock and a calendar to plan when to take medicine.

We are asking you, as experts in adult education, to continue to focus on the skills you help your students develop. We do not ask you to become health experts. Instead, we hope you will be able to focus on skill development within a health context. For example, when you help your students learn to read a chart, you might want to use a weather chart and note that people with asthma (a chronic disease) often need to check the amount of pollen in the air. As a result, you will be making a profound contribution to health literacy.

We hope to engage you in a variety of activities, to encourage you to analyze the needs and interests of your students, and to discuss and develop lessons designed to increase the health literacy of adult learners. We also hope to learn from you. We want to improve the processes and activities of study circles. We plan to add to a compendium of possible lessons and curricula. We encourage you to take an active role in providing feedback to us and in developing lessons to be shared with others.

Sincerely,

Rima Rudd

Rima E. Rudd, Sc. D.
Principal Investigator, Health and Literacy Studies
Harvard School of Public Health

A Letter to Adult Education Practitioners From Lee Hewitt - an ESOL Teacher and Health Curriculum Developer

Dear Colleagues,

I have had many opportunities to work with health content in adult education classes with ESOL learners. Many of these experiences involved the publication of student written stories, plays or essays about health topics. The students gave one such collection the title, *Health is Life - A Treasure To Take Care Of*.

This title I believe captures why it is so important to deal with health issues in an adult education classroom. Good health allows us so many opportunities. Even challenges to our health that are taken care of or well-managed can still allow us to live a life we may treasure.

Over time I have come to realize that one of the most pressing health issues facing many adult education students is in fact literacy itself. Without at least basic literacy skills, the health of any individual in the U.S.A. is compromised. The seemingly simple task of navigating a hospital requires good literacy skills. Without these skills, getting from one place to another may become a humiliating experience. Without these skills, an individual may not be able to communicate valuable information to her health care provider. Without these skills, an individual may never be able to control the path of her own health care experience in a way she wants to or needs to for a truly healthy life.

A number of researchers have examined patients' skills as well as the literacy demands of the health care system and have found a mismatch.¹ For example health care pamphlets frequently are produced at a reading level beyond the reach of many of our adult education students. Unfortunately, the medical

establishment is only slowly recognizing how the limited literacy skills of many of its patients interfere with communication and quality care.

Where does this lead us as adult educators? I believe this leads us back to learning about the literacy issues of our students, so we can teach them the reading, writing and math skills they need. It also leads us back to learning *from* them. How do their literacy challenges influence their daily lives? How do these challenges influence their experiences with the health care system and with maintaining their own health? Most adult educators already invest a lot of time learning about their students. Many seek to learn from them. I believe this is what makes adult educators such a vibrant community of teachers.

I also believe that changes in the medical establishment will come from the learners that we teach who use their developing literacy skills to ask the questions they need to ask- to reach for the words that will clarify their confusion and to write down the truth of their lives.

Sincerely,

Lee Hewitt

ESOL Teacher
Health Curriculum Developer

¹ K. Beaver and K. Kuker. Readability of patient information booklets for women with breast cancer. *Patient Education & Counseling*,31(2):95-102,1993.

A Letter from Charlotte Nath - Nurse and Educator

Spring 2004

Dear Adult Educator,

I have been working with patients with diabetes and other chronic diseases for many years and with patients with low literacy for the last few years. All in all I have learned more from these patients than I have taught them. I learned that some issues regarding self-management were harder to get across than others, particularly those that required problem solving. I learned that some patients had difficulty with calculating time using a digital clock as opposed to an analog clock. I learned that patients often did not understand the purpose of some of the required tasks and therefore did not personally benefit from uncomfortable procedures such as finger sticks. But it was not until a patient was referred to me with known literacy problems that my eyes were truly opened to the issues a person with low literacy faces in the health care environment and to the prevalence of low-literacy in that environment.

As I struggled to prepare for that single teaching encounter I was still equating “literacy” with the ability to “read.” I quickly learned that literacy reflects much more than “reading ability.” For example, a basic skill for diabetes self-care is meal planning where patients learn to identify foods that raise their blood glucose and to limit portion sizes of those foods to match their medication and activity. Persons with limited literacy may have barriers related to categorization skills so that Mr. X could identify an apple from the food models on the table but could not recognize this apple as a member of the “fruit” category. So if Mr. X was directed to eat 4 servings of fruit per day he did not know which foods were in that category. When he was advised to eat more poultry and less red meat, he did not know that “chicken” was poultry.

Almost all patients could learn to use the blood glucose meter correctly and write the results in a logbook. Fewer could actually determine if that result was within the target range and take action for correction if needed. Fewer still could work backward from a blood glucose value to examine their food intake or medication and make an adjustment. These are very important skills for the avoidance of emergency low blood glucose reactions. For example, one woman did not like to eat breakfast and skipped it most days, but was very careful to take her insulin dose in the morning as prescribed. Despite numerous low blood sugar reactions in the mid-morning she had not related these to her habit of skipping breakfast.

While I was able to find materials on how to assess literacy and how to prepare written materials for persons with low literacy, I could not get a handle on what essential elements of my teaching needed to be changed to overcome these barriers. I became a bit obsessed with the issue of literacy and the barriers it

presented. My clinic seemed to swell with low-literacy patients, perhaps because I learned to recognize them more easily.

I was frustrated and wanted to learn more. I was granted study leave to work with Dr. Rima Rudd and others at the Harvard School of Public Health. She introduced me to a myriad of resources but particularly to the role of Adult Basic Education and the potential for a linkage between adult educators and health educators/providers. As part of such a team I was encouraged to identify the specific tasks needed for chronic disease management and then the educators on the team identified the skills required to perform these tasks and how they might be taught in the adult education classroom.

My strengths as a clinician were matched with the strengths of the educator to design a chronic disease study guide for Adult Basic Education and English as Second Language instructors. We laughed over my tendency to get into the nitty-gritty disease-specific tasks only to be pulled back to basic education skills needed to accomplish the tasks. I was forced to revisit basic skill sets such as reading, writing, numeracy, problem solving, oral comprehension and communication and their application to a given task. We performed a lazy kind of dance with me presenting the clinical task (such as drawing a correct dose of insulin or calculating the portion size for a meal) and the educator identifying the basic skill that was required. Together we would come up with examples that might demonstrate the skill.

This experience has convinced me that the health provider and the adult educator make a workable team. Each benefits from the other's skills. I will certainly work to establish a partnership with adult educators when I get back home to explore what we can accomplish together to further the goal of improved communication and teaching related to chronic disease management. This partnership will benefit the provider, the educator and most importantly, the patient.

Sincerely,

Charlotte Nath

Charlotte Nath, RN, Ed.D.

Guiding Questions for *A Maturing Partnership*

Consider these questions before and after you read the following article, *A Maturing Partnership* by Rima E. Rudd. You do not need to write out your answers to these questions but you may want to bring your thoughts about these questions into discussions and activities during the study circle sessions.

General Questions

1. Does the cited evidence support a relationship between health outcomes and educational achievement?
2. Which of the many events in the fields of public health or adult literacy contributed the most to our understanding of the link between health outcomes and literacy skills?
3. Is the author's description of the influence of health education on adult education curricula consistent with your experience or knowledge?
4. What are the implications in the shift in focus from *health content* to *health-related tasks and literacy skills* for your teaching?

Connections to Chronic Disease Management

1. Imagine it is the year 2010 and the federal initiative *Healthy People 2010* and its focus on health literacy are deemed a success. In what ways would you hope to see improvements in adult learners' basic skills related to managing a chronic disease?
2. What aspect of this article was most relevant to you as you think about how you might go about teaching basic skills with respect to chronic disease management in your own classroom?

A Maturing Partnership *

by Rima E. Rudd

How did the literacy and health fields come to work together? Now that this partnership, tentative as it is, has begun, what direction should it take? As a public health researcher, I have worked to bring these two worlds together, believing passionately that the relationship will be beneficial for both fields, and, most importantly, for the clients of the health and literacy systems. In this article I will trace early innovations in this movement, through some current activities, and provide some suggestions for next steps.

Demographic information such as measures of age, race, income, and education are traditionally collected in all health surveys so that researchers can examine differences among various population groups. Two of these items, income and education, are considered measures of socioeconomic status. We have strong evidence that socioeconomic status and health are linked. Of course, adult educators who work with low-income learners will not be surprised to learn that those who are poor or have lower educational achievement have more health problems than do those with higher income or higher educational achievement.

The Secretary of Health and Human Services prepares an annual report to the President and Congress on national trends in health statistics, highlighting a different area each year. The 1998 report focused specifically on socioeconomic status and health (Pamuk et al., 1998). This report offered evidence from accumulated studies that health, morbidity — the rate of incidence of a disease — and mortality are related to socioeconomic factors. For example, life expectancy is related to family income. So, too, are death rates from cancer and heart disease, incidences of diabetes and hypertension, and use of health services. Furthermore, death rates for chronic disease, communicable diseases, and injuries are inversely related to education: those with lower education achievement are more likely to die of a chronic disease than are those with higher education achievement. In addition, those with less than a high school education have higher rates of suicide, homicide, cigarette smoking, and heavy alcohol use than do those with higher education. The lower your income or educational achievement, the poorer your health.

Thus, links between critical health outcomes and income/education are well established. However, until recently, health researchers had not examined any particular components of education such as literacy skills. This is because education itself was not the major consideration; education was only considered a marker of social status. Another barrier to examining any specific role that education might play was that specific skills such as literacy were not consistently defined or measured. A number of events have led some researchers

* FOCUS ON BASICS, Volume 5, Issue C • February 2002. World Education, NCSALL

to explore the possibility that limited literacy skills might influence a person's health behaviors and health outcomes.

Key Events

Dozens of articles in the 1980s and scores of articles in the early 1990s offered evidence that written documents in the health field were very demanding and were often assessed at reading levels beyond high school (Rudd et al., 1999a). While this comes as no surprise to anyone who tries to read the inserts in over-the-counter medicines, what is common knowledge had never been systematically documented.

In addition, a number of health analysts writing in the 1980s had noted connections between illiteracy and health (for example, Grueninger, 1986; Kappel, 1988). A literature review published in the *Annual Review of Public Health* highlighted growing evidence in international studies that a mother's literacy was linked to her child's health (Grosse & Auffrey, 1989). In 1991, the US Department of Health and Human Services published *Literacy and Health in the United States* (Aspen Systems Corp., 1991), which highlighted the importance of paying attention to literacy issues. It offered an annotated bibliography of journal articles and books that assessed health materials as well as studies that showed a relationship between literacy skills and health-related knowledge and behaviors. For example, some differences between people with high educational achievement and those who reported that they could not read were noted (Perrin, 1989; Weiss et al., 1991). A number of studies conducted in Ontario, Canada, drew attention as well (Breen, 1993).

The main focus of most of the literacy and health inquiries, however, were studies of the reading level of written health education materials. Among those researching this subject was Terry Davis, a medical school faculty member and researcher (Davis et al., 1990). Davis and colleagues wanted an easy-to-use tool to assess and document the reading level of patients so that they could study some health-related differences between people with limited and with strong literacy skills. They developed and tested a health-related literacy assessment tool called the Rapid Estimate of Adult Literacy in Medicine, or REALM (Davis et al., 1991). This tool enabled them to examine differences between people with high and low scores for literacy and health behavior differences, such as engaging in screening tests for early disease detection.

Later, for example, Davis and colleagues found that women with limited literacy skills did not understand the purpose of a mammogram and did not access screening (Davis et al., 1996). The REALM tests a person's ability to read through a list of medical words, moving from short and easy words to difficult and multi-syllabic words. It correlates well with reading tests and offers a good marker of literacy level. This tool helped a small group of researchers around the country to make health-related comparisons between those with and without strong literacy skills.

Further interest in this type of research was fueled by the first national assessment of functional literacy skills. The 1993 publication of the first wave of analysis of the National Adult Literacy Survey and the findings that half of the US adult population had limited literacy skills provided critical information (Kirsch et al., 1993). The National Adult Literacy Survey (NALS) focused on functional literacy, defined in the National Literacy Act of 1991 as “an individual’s ability to read, write and speak in English, and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one’s goals, and develop one’s knowledge and potential.”

The NALS measured people’s ability to use the written word for everyday tasks. Thus, people’s functional literacy skills were examined in terms of their ability to find and apply information from commonly available materials such as newspapers (prose), forms (documents), and common math processes such as computation for addition or percentages (numeracy). The NALS established a uniform measure of functional literacy and offered a portrait of literacy among adults in the United States. Fully 47 to 51 percent of adults scored in the lower range: unable to use the written word to accomplish many everyday tasks such as finding a fact or two in a newspaper article, finding information on a Social Security form, or calculating the tip on a bill.

This information was a wake-up call to some researchers in the health field. We must remember that it takes a while for information to spread and, especially, to cross over disciplinary lines. Of course, the 1993 NALS findings are still “news” to many people in health and even in education (see the side bar on page 8 for a discussion of the diffusion process). But, as a result of these published findings, some health researchers began to think about people’s ability to function in health care settings and carry through with tasks many doctors and nurses take for granted: the ability to read announcements and learn about screening, to read directions on medicine labels, to follow recommended action for self-care.

Among those at the forefront were Ruth Parker and Mark Williams, medical doctors practicing in a public hospital in Atlanta. They were interested in measuring and documenting people’s functional literacy skills related to medical tasks. In 1995, Parker and Williams worked with colleagues in education and measured people’s ability to read appointment slips, medicine labels, and informed consent documents. They then used these tasks to develop a functional test of health literacy for adults in both English and Spanish (TOFHLA) modeled on the NALS. Studies undertaken by a team of researchers working with patients in a public hospital indicated that 41 percent of patients did not understand basic instructions, 26 percent did not understand appointment slips, and 60 percent did not understand informed consent forms (Parker et al., 1995; Williams et al., 1995). Findings from these studies are being used to convince doctors that literacy is something to which attention should be paid.

With the development of the REALM (1991) and the TOFHLA (1995), people assessing the readability of written health materials could now more precisely examine the match between the materials and the reading ability of members of the intended audience. Furthermore, researchers now had tools for a quick assessment of literacy skills so that they could include measures of literacy in health studies. As a result, we've learned that people with low literacy skills come into care with more advanced stages of prostate cancer (Bennett et al., 1998); that they have less knowledge of disease, medication, and protocols for asthma, hypertension, and diabetes (Williams et al., 1996, 1998); and that they are more likely to be hospitalized than are patients with adequate literacy (Baker et al., 1998). These studies set the foundation for rigorous research into ways that limited literacy skills may affect health.

On the Literacy Side

Health topics have long been included in curricula for students in adult basic education (ABE) classes and in English for speakers of other languages (ESOL) courses. Making appointments and identifying body parts in English were seen as necessary survival skills, particularly, for example, in refugee resettlement classes in the 1980s. Topics such as nutrition and hygiene were popular with many teachers, who reported that health issues interested their students and could be used as the subject of reading materials for developing reading and writing skills (Rudd et al., 1999a).

In the early 1990s, links were being forged between health educators and adult educators. For several years, the National Cancer Institute supported regular working group meetings of health and education researchers. Local initiatives such as those developed by Sue Stableford at a medical school in Maine, Kathy Coyne at a cancer center in Colorado, and Lauren McGrail at a nonprofit organization in Massachusetts worked across disciplinary lines and linked health researchers and practitioners with adult educators. They could now work together on developing appropriate health materials and on bringing health curricula to adult education programs. Over time, some model program funds from the National Institutes of Health, the Centers for Disease Control and Health Promotion, and, in some cases, state Departments of Public Health, supported the development of adult education curricula in specific topic areas such as breast and cervical cancer or smoking prevention. The idea of integrating health topics into adult learning centers was based on the assumption that health curricula would enhance the goals of the health field while also supporting the goals of adult education. Health practitioners working with the adult education systems gained access to and communicated with adults who are not reached through the more traditional health outreach efforts and communication channels. Thus, adult education learning centers provided the health field with an ideal site for reaching poor, minority, and medically underserved populations.

Bringing health topics to adult education programs was similarly viewed as beneficial to the adult education system. Teachers focused on health-related lessons would be building skills for full participation in society. In fact, NCSALL studies indicated that state directors and teachers considered that a health-related content would likely engage adult students and thereby increase learner interest, motivation, and persistence (Rudd et al., 1999a, b). Several curricula, such as the *Health Promotion for Adult Literacy Students* (1997), *Rosalie's Neighborhood*, *What the HEALTH?*, and *HEAL: Breast and Cervical Cancer* offered substantive full curricula for teachers who wished to offer in-depth health lessons incorporating basic skill development. However, the NCSALL survey revealed that teachers' and directors' were cautious about the appropriateness of asking adult education teachers to teach health content. This is not, after all, their area of expertise.

Literacy for Health Action

Teachers' and directors' discomfort with responsibility for certain health information led a number of us working in this area to move away from a focus on health content towards a closer examination of literacy skills needed for health-related action. After all, adult educators have the expertise to help learners build basic skills related to reading, writing, vocabulary, verbal presentation, oral comprehension, as well as math. These skills are critical for adults who need to fill out insurance and medical forms, describe or monitor symptoms, manage a chronic disease, listen to recommendations, and make health-related purchases and decisions. Furthermore, many of us were interested in expanding our work beyond the medical care setting and a focus on disease to a more public health focus with attention to maintaining health at home and in the community.

New opportunities for productive partnerships may come about because of a growing emphasis on health literacy. The term has been defined in several ways. The US Department of Health and Human (HHS) Services' publication *Healthy People 2010* defined health literacy in terms of functional literacy related to health tasks: "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (US DHHS, 2001). This definition, although focused on health care, is general enough to include health-related activities outside of medical care settings such as maintaining our well being, caring for ourselves and others, and protecting our health at home, in the community, and on the job. Tasks can include reading a patient education brochure, deciding whether to buy a brand of food based on nutritional labeling, figuring out how to use a particular product, or choosing a health insurance plan.

A partnership between the US Department of Health and Human Services and the developers for the National Assessment of Adult Literacy (NAALS) planned for 2002 led to the inclusion of health-related tasks in this second wave of adult literacy assessment. Therefore, the 2002 NAALS will include three different

clusters of key types of health and health care information and services that the general population is likely to face, identified as clinical, prevention, and navigation. The clinical area will include activities such as filling out patient information forms or determining how to take a medicine. The prevention area will include tasks such as identifying needed changes in eating or exercise habits. Finally, the navigation area will include tasks related to understanding rights in health care or finding information in health insurance plans.

In addition, health literacy is included in the goals and objectives for the health of the nation. *Healthy People 2010* is the planning document that sets health objectives for the nation and is used in national and state plans and to shape requests for proposals for federal funds. It offers 467 objectives in 28 focus areas, making this decade's report, according to the Surgeon General's report, an encyclopedic compilation of health improvement opportunities (US DHHS, 2001). This document now includes literacy-related objectives for the first time. Objective 11.2 is *to improve the health literacy of persons with inadequate or marginal literacy skills*. The listing of a specific literacy-related objective is listed under health communication and is also referenced under oral health. This attention is viewed as a milestone.

Professionals in public health and health care do not have the skills or mechanisms to improve the literacy skills of their community population or of their patients. They can, however, work to improve their own communication skills, the procedures followed for communicating with and interacting with people, and the forms and materials they write. Health workers at all levels would benefit from interactions with adult educators who could help them better understand the communication needs and learning styles of people with limited literacy skills. In addition, those in the health field are increasingly aware that a population with good literacy skills may make better use of health information and health services than those with limited skills. The potential benefits from partnerships between those in the health fields and those in adult education are becoming clearer.

New Collaborations

The health literacy objective in *HP 2010* may offer new and different opportunities for collaboration between practitioners in health and in education. Many of the early partnerships, as noted above, were focused on bringing health-related topics and curricula to basic education or language programs. The emphasis was on bringing new information to adult learners. Because the health literacy objective in *HP 2010* focuses on skills, new partnerships may more easily emphasize health-related tasks and related literacy skills rather than specific health topic areas such as cancer or diabetes.

Adults take health-related action in multiple settings; they determine priorities and consult and solve problems with family, friends, neighbors, and fellow workers about health-related issues and actions. In today's society, adults may need to find information on the Internet, differentiate fact from myth, or establish the source of information. Thus, skill-building opportunities related to forms, directions, and information packets are important but do not suffice.

For example, adults who have accessed care and successfully developed the needed skills to follow the complicated regimen to manage asthma may still face difficulties with asthma triggers beyond their control. Living in a multifamily dwelling with exposure to cigarette smoke, dust, mold, mildew or roaches; living in a neighborhood with heavy traffic or idling buses; and working with a variety of chemicals all have asthma-related consequences. Becoming aware of new findings, gathering information, participating in tenants' associations, and involvement in community or labor action groups require skills related to research, discussion, analysis, decision making, and action. Thus, as we explore this area and define needed skills, we must be sure to move beyond the realm of medical care and include action taken at home, at work, in the community, and in the policy arena.

Many of these broader communication skills are already being taught in adult education programs. Adult educators focus on language and vocabulary acquisition, reading, writing, numeracy, oral comprehension, dialogue, and discussion. Their expertise can support and enhance health literacy goals. Health-related curricula incorporating attention to these skills can enrich adult learners' experiences and will support health literacy goals. With a focus on health literacy skills, the *HP 2010* objectives will encourage health practitioners to work with adult educators on the delineation of needed skills to support health literacy rather than on a transfer of health information.

Another task is at hand as well. Many of the health-related literacy tasks under discussion involve the use of existing medical documents such as appointment slips, consent forms, and prescriptions. An underlying assumption is that the materials and directions are clear and appropriately written. Yet, we know from the results of more than 200 studies that the reading level of most health materials is well beyond the reading ability of the average reader and that the format or presentation of information is similarly inappropriate (Rudd, 1999a). The links between literacy skills and oral comprehension have not been explored in health studies and the vocabulary of medicine and health may well provide barriers in spoken exchange.

Twofold Strategies

As a consequence of these findings, strategies must be twofold: increase adults' health-related literacy skills and increase health professionals' communication skills. Adult educators can contribute to these efforts. Their skills and experience

can help health professionals to understand better the factors that contribute to reading and oral comprehension. Educators can also help health professionals to improve written materials and, perhaps, verbal presentation of information as well. The Canadian Public Health Association, for example, has mandated that all materials geared for the general public use so-called plain language and avoid the jargon, scientific vocabulary, and complex sentences that make materials difficult to read. Accreditation committees are increasingly encouraging hospitals and health centers to examine and redesign their documents and procedures for informed consent. Expert advice from adult education professionals will clearly be needed and welcomed.

A new partnership between health and adult education researchers and practitioners can also contribute to improved teaching and learning in both fields. Studies of participatory programs, participatory pedagogy, and efficacy-building in classrooms, community programs, and doctors' offices indicate that learning is enhanced and change is supported through experiential learning opportunities. Roter and colleagues (2001), for example, provide evidence for the value of adopting lessons from participatory pedagogy in doctor/patient encounters. Minkler (1989) and Green and Kreuter (1999) have long supported such approaches for health promotion on the group and community levels. However, participatory programs and experiential learning are still not the norm in either health or adult education settings. Perhaps partnerships among practitioners in both fields will lead to rich explorations of approaches that support adult learning.

Health literacy is a new concept that is getting a good deal of attention. We can support healthful action by considering the skills needed for active engagement and by envisioning the adult, healthy or ill, as an active partner and decision maker. Educators, researchers, and practitioners can work together to explore strategies for improving communication, increasing needed skills, and fostering efficacy.

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Background Information and Useful Definitions for Chronic Disease Management

Adult educators do not need to become health experts, nor do they need to learn all there is to know about chronic diseases or about how to manage chronic diseases. However, adult educators are experts in literacy and already teach an array of skills that are very important for people who must manage a chronic disease. This brief background reading sets a foundation for the discussions in this study circle.

Changes in the Health of Americans

During the last century, the health of Americans has improved and so has longevity. Scientific advances have led to disease prevention, to early detection and treatment, and to management of diseases that cannot be cured. Furthermore, serious consequences of many diseases are now preventable. As a result, many people with heart disease survive episodes such as heart attacks or strokes. New findings, new medicines, and new procedures have helped doctors make early diagnoses, cure some diseases, and treat others over the long term. More people are living longer than in previous generations. At the same time, many older adults live with one or more diseases. Sadly, even with modern medicine, some diseases, such as arthritis, still result in pain and suffering and decreased quality of life for millions of Americans.

Disease

The word disease actually means *lack of ease*. The word *disease* is used to describe a condition of the body that is considered abnormal. When a disease is present, the body or parts of the body do not act as they normally do. In addition, a disease presents a group of symptoms specific to it. A doctor is trained to diagnose many diseases by looking for a group of specific symptoms. You will find that people use many different words when they talk or write about *disease* and these include *condition*, *problem*, and *long-term illness*.

Types of Disease

Diseases can be classified as *acute*, *chronic*, *endemic*, *familial*, *hereditary*, *occupational*, *parasitic*, or *systemic*. These different types are based on how the disease develops, where the disease develops, or whether or not the disease goes away or stays with you.

Here are two definitions from the ***Taber's Cyclopedic Medical Dictionary***:

- ***Acute disease***: A disease having a rapid onset and of relatively short duration
- ***Chronic disease***: A disease having a slow onset and lasting for a long period of time

Those people with an *acute disease* or injury who seek care are treated. Sometimes they stay in a hospital and are discharged when they are better.

On the other hand, people often use the term *chronic disease* to mean a disease that has no known cure. The most common *chronic diseases* are: heart disease, cancer, stroke, arthritis, lung disease (chronic obstructive pulmonary disease), diabetes, kidney disease, and asthma. Those people with a chronic disease must seek care and develop a partnership with health care providers. Over time, people with a chronic disease will interact with health care providers on a regular basis. They must often make changes in their lives and adopt new behaviors at home or at work. They are expected to work with their health care team to manage their disease.

In many ways, people with a chronic disease have more personal responsibility for their care than do patients with an acute disease. In addition, unlike people in a hospital, people with a chronic disease are engaged in activities of everyday life. They often have to teach others about their chronic disease. They sometimes have to make modifications at home, at work, and in the community.

Disease Management

When people talk about disease management, they usually refer to chronic disease. Chronic diseases cannot be cured but they can be *managed*. People with a chronic disease must make changes in how they live their lives. They must also take specific actions, often on a daily basis. A person with a chronic disease is expected to:

- Engage in activities that promote health
 - For example: Purchase, prepare, and eat healthy food.
- Engage in activities that protect health
 - For example: A person with asthma is expected to avoid places where people smoke.
- Monitor symptoms and signs of illness
 - For example: Pay attention to the feelings associated with disease such as shortness of breath or the onset of a rash; make note of what happens and when it happens and then talk about this with a doctor or nurse.
- Manage symptoms
 - For example: Follow a plan or take a specific medicine when a certain symptom comes on.
- Manage the impact of the illness
 - For example: Decrease or increase physical activity when needed.

- Manage a care plan
 - For example: Plan and keep appointments or remember to take the proper amount of medicine according to a schedule.

- Manage the emotional side of illness and its impact on relationships with family, loved ones, friends, and co-workers
 - For example: Help people understand that some symptoms come and go over time and that some diseases have flare ups.

All of these activities involve a complex array of skills.

Kate Lorig and colleagues discuss these and other actions in their book: *Living a Healthy Life with Chronic Conditions*. They point out the following:

“... The central management tasks and skills one must learn to live with different chronic illnesses are similar. Besides overcoming physical and emotional problems, you must learn problem-solving skills and how to respond to the trends in your disease. These tasks and skills include developing and maintaining exercise and nutrition programs, managing symptoms, making decisions about when to seek medical help, working effectively with your doctor, using medications and minimizing side effects, finding and using community resources, talking about your illness with family and friends, and, if necessary, changing social activities. Maybe the most important skill of all is learning to respond to your illness on an on-going basis to solve day-to-day problems as they arise.”
(p.6)

Lorig and colleagues point out that a manager has many responsibilities:

“...They don't do everything themselves; they work with others, including consultants, to get the job done. What makes them managers is that they are responsible for making the decisions and making sure these decisions are carried out. As a manager of your illness, your job is much the same. You gather information and hire a consultant, or a team of consultants consisting of your physician and other health professionals. Once they have given you their best advice, it is up to you to follow through. All chronic illness needs day-to-day management...Some of the most successful self-managers are people who think of their illness as a path. This path, like any path, goes up and down. Sometimes it is flat and smooth. At other times the way is rough. To negotiate this path one has to use many strategies. Sometimes you can go fast, other times you must slow down. There are obstacles to negotiate. Good self-managers are people who have learned the skills to negotiate this path.” (pp. 11-12)

The last line of the quote above notes the importance of skills. To date, most medical, nursing, or dental discussions and materials do not focus on tasks and skills. Many health practitioners do not understand the underlying literacy skills needed to accomplish the many tasks of chronic disease management. Sometimes, professionals take these literacy skills for granted. For example, people are expected to read materials about their disease that include medical

words and scientific concepts. They are expected to be able to use a clock or a calendar and plan out their medicines. They are expected to have the words needed to describe a feeling.

Symptom

According to the *Taber's Cyclopedic Medical Dictionary*, a symptom is described as *a perceptible change in the body or its functions that indicates disease*.

When *symptoms* can be observed or measured by a doctor, they are often called *signs*. Doctors are trained to link sets of symptoms with particular diseases or disorders.

Many people also use the word *symptom* to describe feelings. The dictionary offers two ways to think about the word: as subjective or as objective:

- A subjective symptom – is experienced or felt by the person (for example: nausea or pain).
- An objective symptom – An objective symptom can be observed or measured by others (such as a rash or limp). Professionals might also be able to observe or measure a symptom with the use of special equipment (for example: blood pressure as measured by a blood pressure cuff, a tumor as seen on film from an X-Ray, MRI, or CAT Scan).

In Conclusion

This study circle focuses on health literacy skills for chronic disease management. As participants, you are invited to consider the different kinds of activities involved in the management of any chronic disease. Next, you will be asked to identify skills that adult learners need to master so that they can accomplish tasks common to the management of all chronic diseases. Some of these tasks have to do with the application of basic math, the use of measurement scales, or the ability to find words to communicate feelings. The authors of this study circle believe that your understanding of needed skills and your ability to teach these skills make and will make profound contributions to the health of all adults.

At the same time, the authors hope that this work will help you and others identify literacy related barriers to health care and to healthful outcomes. Chronic disease management is difficult enough and ought not to include unnecessary barriers such as the use of medical jargon or poorly written and complicated directions. Together, we can all work for change.

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U.S. Department of Health and Human Services: National Institutes of Health at <http://www.nih.gov/>.

Shared Goals but Different Roles in Health Literacy

What medical professionals should do...



- Make health care services and resources available
- Offer and explain appropriate screening procedures
- Diagnose illnesses and develop a plan for patient care
- Prescribe medicines and explain their purposes and side effects
- Teach patients how to use medical tools, such as inhalers and glucose meters
- Suggest measures to protect individual and family health

What adult educators can do...



- Enhance students' ability to complete forms, make inquiries for information, and navigate new environments
- Teach students to ask questions about tests, test procedures, and results
- Develop students' capacity to participate in planning by seeking clarification and offering suggestions
- Teach students how to read medicine labels, calculate amounts and timing of dosages
- Strengthen students' ability to read charts and scales and interpret ranges
- Help students learn to locate information to guide their health-related decisions

Additional Resources

(For Your Information)

The following materials may help you explore, understand, and engage in an active dialogue around the issues of health literacy and chronic disease management. This list includes links to health related Web sites such as National Institutes of Health, the U. S. Food and Drug Administration, the Center for Disease Control, Medline Plus, and WebMD.

This information is meant to serve as a resource for you in your work on health literacy and chronic disease management. You do not need to read or review all of the materials listed below, but do look through them and read the ones of interest to you.

These materials are organized in the following categories:

- Research on Health Literacy
- General Topics for Chronic Disease Management
- Teaching Resources
- Communicating with Your Doctor
- Managing Medications
- Managing Asthma
- Managing Diabetes
- Understanding Food Labels

Research on Health Literacy

Findings from a National Survey of State Directors of Adult Education

Rudd, R., Zahner, L. & Banh, M. (1999).

(NCSALL Report #9)

Available online at: <http://www.ncsall.net/?id=673>

Summary: State Directors of Adult Education were asked to consider health within the context of adult learning and to offer priority ratings for health as a content area through which other skills may be taught, as a subject of study, as a skill area, and as a barrier to learning. In addition, directors were asked to list barriers to incorporating health lessons in adult learning centers and to identify concerns or considerations that must be addressed. Additional commentary was invited.

The survey response rate was 88%. The state directors offered relatively high priority ratings for health issues, with mean ratings between 3 and 4 on a five point scale (1 indicating low priority and 5 indicating high priority.) The most frequently listed barriers were lack of curriculum on health and lack of teacher training. They identified a variety of concerns with a strong emphasis on structural issues and resources.

Integrating Health and Literacy: Adult Educators' Experiences

Rudd, R., Zacharia, C. & Daube, K. (1998).

(NCSALL Report #5)

Available online at: <http://www.ncsall.net/?id=672>

Summary: This exploratory study addresses the experience of adult educators in Massachusetts who have integrated a health unit into adult education classes focused on reading, writing, and communication skill development. Health as a topic area may serve to motivate learners and support critical skill development and, at the same time, offer a venue in which health issues and information can be presented, discussed, and critically analyzed. This study focuses on the teachers' perceptions of advantages and disadvantages of a focus on health.

The participating teachers indicated that health units helped them meet classroom objectives and supported the teaching of reading, writing, vocabulary building, and speaking skills. Teachers noted that they value health as a subject of study because of its relevance to learners' lives and that their learners were interested and motivated to read or write on health issues and speak in class or in groups about the subject.

The findings from this study have implications for program designers and practitioners in the fields of education and public health.

Health and Literacy: A Review of Medical and Public Health Literature

Rudd, R., Moeykens, B.A., & Colton, T. (1999).

The Annual Review of Adult Learning and Literacy, Vol. 1: Chapter Five
Available on line at: <http://www.ncsall.net/?id=522>

Summary: In Chapter Five of *The Annual Review of Adult Learning and Literacy*, Vol. 1:, Rima Rudd, Barbara A. Moeykens and Tayla C. Colton share their examination of the medical and public health literature regarding links between health and literacy and identify trends in research and practice. Education may influence lifestyle behaviors, problem-solving abilities, and values. Literacy has been shown to be related to patients' ability to describe their own symptoms, which can in turn influence the care that they receive. Further, literacy has been demonstrated to directly influence patients' access to information on their rights and health care, including instructions and understanding of preventative measures and risks involved in medical procedures.

Too often, research shows, the literacy demands of material encountered by patients exceed the literacy abilities of the readers. For example, this has been found to be the case with informed-consent materials, package inserts and a variety of health education materials on topics including diabetes, prenatal care, and cancer, among others.

The authors also reveal the relationships shown between literacy and health outcomes. Lower levels of literacy are clearly associated with poorer health, and low levels of health literacy have a measurable impact on screening and early detection. The authors recommend strategies for improving communication with patients, including improved readability of materials, involvement of patients in designing more effective materials, and education of health care providers on the needs of low-literacy populations.

Rudd, Moeykens and Colton call for more research on the relationship between levels of health literacy and health outcomes, the intermediate factors that influence health outcomes, and health care costs. They stress the need for continued efforts to develop strategies to address the special needs of those with low health literacy. The authors close by describing some exemplary projects that illustrate the potential for effective collaboration between professionals in education and health in seeking to meet the needs of less literate populations.

An Overview of Medical and Public Health Literature Addressing Literacy Issues: An Annotated Bibliography

Rudd, R., Colton, T. & Schacht, R. (2000).
(NCSALL Report #14)

This annotated bibliography is updated yearly and can be found on the Web site at <http://www.ncsall.net/?id=665>

This bibliography includes 241 citations that are arranged in the following categorical groups:

- Links between literacy and health;
- Literacy levels of patients, clients, or program participants;
- Match between reading ability and written materials;
- Functional literacy and institutional settings;
- Materials assessments;
- Research tools for assessing health literacy;
- Program descriptions; and
- Guidelines for practice.

Health Literacy Studies: The Harvard School of Public Health

(from the Department of Society, Human Development and Health at the Harvard School of Public Health)

Available at: <http://www.hsph.harvard.edu/healthliteracy>

Summary: The Health Literacy Studies Web site is designed for professionals in health and education who are interested in health literacy.

General Topics for Chronic Disease Management

National Institutes of Health (NIH)

Available online at: <http://www.nih.gov/>

Summary: The National Institutes of Health is an agency under the U.S. Department of Health and Human Services. Its mission is science in pursuit of fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to extend healthy life and reduce the burdens of illness and disability. Health information is organized with an A-Z index of NIH health resources, clinical trials, health hotlines, MEDLINEplus, and drug information.

Coping with Chronic Illness

(from the National Institute of Health)

Available online at:

http://www.cc.nih.gov/ccc/patient_education/pepubs/copechron.pdf

Summary: This information was prepared to help patients and their families cope with chronic illness. It contains quotes from adult Clinical Center patients who face a variety of medical problems.

Easy to Read Publications

(From the U. S. Food and Drug Administration)

Available online at: <http://www.fda.gov/opacom/lowlit/englow.html>

Summary: The FDA provides easy-to-read health brochures in both English and Spanish. These brochures are available on this Web site in both PDF and HTML formats. Some of the titles you will find at this Web site include:

- Eating for a Healthy Heart (FDA 00-2302)
- How to Give Medicine to Children (FDA 00-3228)
- Medicines and Older Adults (FDA 00-3237)
- Use Medicine Safely (FDA 00-3201)
- Help Your Arthritis Treatment Work (FDA 00-1270)
- Quick Information-Diabetes (FDA 02-3238)

Healthy Roads Media

Available online at: <http://www.healthyroadsmedia.org/>

Summary: This site contains free audio, written, and multimedia health education materials in a number of languages on topics including Asthma, Cancer, Dental Health, Diabetes, Health Services, Your Heart, Immunizations, Nutrition, and Exercise.

Your Disease Risks

(from The Harvard Center for Cancer Prevention)

Available online at: <http://www.yourdiseaserisk.harvard.edu/>

Summary: This educational Web site was developed by the Harvard Center for Cancer Prevention. Based at the Harvard School of Public Health, the Center promotes prevention as the primary approach to controlling cancer and other chronic diseases. This site offers a quick survey to find out your risk of developing five of the most important diseases in the United States (Cancer, Diabetes, Heart Disease, Osteoporosis, and Stroke) and get personalized tips for preventing them.

Centers for Disease Control and Health Promotion

Available online at: <http://www.cdc.gov/>

Summary: The Centers for Disease Control and Prevention (CDC) is a federal agency that focuses on protecting the health and safety of people - at home and abroad - providing credible information to enhance health decisions, and promoting health through strong partnerships. CDC serves as the national focus for developing and applying disease prevention and control, environmental health, and health promotion and education activities designed to improve the health of the people of the United States. Web sites from CDC contain a variety of topics and are updated for use by the general public.

1on1health

(The content in the 1on1health program was developed by GlaxoSmithKline in association with WebMD)

Available online at: <http://www.1on1health.com>

Summary: This Web site contains information, tools and activities to help you live a healthier life and better manage your condition. Information is presented in English and Spanish. Topics include Anxiety Disorders, Asthma, Bipolar Disorder, Depression, Diabetes - Type 2, Enlarged Prostate, Erectile Function, Heart Failure, Herpes, High Blood Pressure, Migraine, Nasal Allergies, Obesity, Osteoarthritis, Restless Legs Syndrome, and Vaccines.

What's in a number: Learn the meaning behind all those tests the doctors put you through

(from The Detroit News: Article written by Tracy Boyd, Tuesday, October 24, 2000)

Available online at:

<http://www.detnews.com/2000/health/1024/main/main.htm>

Summary: Too many people don't have a clue what medical tests mean. If your doctor says your blood pressure is 140/97, cholesterol is 203 and glucose is 130, does that mean you're basically healthy or a heart attack waiting to happen? Are you at risk for diabetes? Should you change your diet? This article discusses four tests (Blood pressure, Body mass index, Cholesterol, and Glucose), including why you need to know your score, what the numbers mean, and how to improve your results.

Understanding Your Tests: Reference Ranges and What They Mean

(from Lab Tests Online, a public resource on clinical lab testing)

Available online at:

http://www.labtestsonline.org/understanding/features/ref_ranges.html

Summary: Test results are usually interpreted based on their relation to a reference range. This article will help to explain what a reference range is, what it isn't, and why test results and references ranges should not be interpreted together in a vacuum. The interpretation of any clinical laboratory test involves an important concept in comparing the patient's results to the test's "reference range." (It's also commonly called the "normal range" but today reference range is considered a more descriptive term. This article defines "reference ranges" and explains what they mean.)

Teaching Resources

The Virginia Adult Education Health Literacy Toolkit

(from The Virginia Adult Learning Resource Center)

Available online at <http://www.aelweb.vcu.edu/publications/healthlit/>

Summary: This Toolkit is a resource to help adult education instructors and administrators better understand the problem of health literacy as it affects their learners. It is designed to support creative approaches to help learners increase health literacy as they engage in sound, productive adult literacy instruction. Information and resources are provided to educate the educator about health care in the United States and cultural issues relating to health, and to simplify creation of health lessons and curricula for teachers and programs.

Communicating with Your Doctor

Talking With Your Doctor

(from Medline Plus, a service of the U. S. National Library of Medicine and the National Institutes of Health)

Available online at:

<http://www.nlm.nih.gov/medlineplus/talkingwithyourdoctor.html>

Summary: This Web site contains links to articles about talking to health care professionals. Subjects include Talking to Your Doctor, Tips for Talking to Healthcare Professionals, Getting a Second Opinion, How to Talk to Your Child's Doctor, Talking to the Pharmacist, and more.

Managing Medications

Over the Counter: Understand Your Medicine Labels

(from the National Consumers League)

Available online at: <http://www.nclnet.org/OTClables/Labels.html>

Summary: This site provides basic information about how to read over the counter medicine labels.

The New Over the Counter Medicine Label

(from the U. S. Food and Drug Administration)

Available online at: <http://www.fda.gov/cder/consumerinfo/OTClablel.htm>

Summary: This site shows an example of what the new over-the-counter medicine (OTC) medicine label looks like.

Medications — Prescription Medicine

(from the Medical Library, the American Academy of Pediatrics)

Available online at:

http://www.medem.com/MedLB/article_detailb.cfm?article_ID=ZZZLJJXTQ7C&sub_cat=0

Summary: If your child needs a prescription medication, it is very important that you understand the pediatrician's and pharmacist's instructions. This list of questions will help you find out all you need to know. This site provides basic information about prescription medications.

Medications — Using the Correct Dosing Device

(from the Medical Library, the American Academy of Pediatrics)

Available online at:

http://www.medem.com/MedLB/article_detailb.cfm?article_ID=ZZZV03SH03D&sub_cat=0

Summary: Many children's medications come in liquid form because they are easier to swallow than pills. But they must be used correctly. Too often parents misread the directions, giving children several times the recommended dosage. This can be very dangerous, especially if given over a period of several days. This Web site offers advice on how to give the proper dose of medication to your child.

Taking Medicines Safely

(from the National Institutes of Health)

Available online at:

<http://nihseniorhealth.gov/takingmedicines/takingmedicinessafely/01.html>

Summary: This reader-friendly site has sections on how to take medicines and manage medicines. The site includes lots of good information, such as questions to ask a doctor about your medications, a simple medication record, and an on-line quiz to check understanding of the material. The FAQs are informative too. Some information is presented through video clips.

Medications — Taking Medicine Correctly

(from the Medical Library, the American Academy of Pediatrics)

Available online at:

http://www.medem.com/MedLB/article_detailb.cfm?article_ID=ZZZYLAKE03D&sub_cat=0

Summary: Research shows that up to half of children who take medications do not take them properly. For your child's prescription or OTC (over-the-counter medicine) to work the way that it should, it is important to follow exact guidelines for its use. This site offers advice on how to give medications to your child.

Medications — The Importance of Reading the Label

(from the Medical Library, the American Academy of Pediatrics)

Available online at:

http://www.medem.com/MedLB/article_detailb.cfm?article_ID=ZZZF7LSYQ7C&sub_cat=0

Summary: If your child needs a prescription medication, a doctor must order the prescription for you. It is very important that you understand the pediatrician's and pharmacist's instructions. This site contains a list of questions to help you find out all you need to know.

Request a Brown-Bag Check-up

(from the Institute for Safe Medication Practices)

Available online at: <http://www.ismp.org/Consumer/BrownBag.html>

Summary: If you have a chronic condition, you may routinely take many different kinds of medications. Often, the dose or times of the medication may need to be adjusted as your health changes. Sometimes, you may also have medications ordered by different doctors, particularly if you visit a number of specialists. These situations can lead to a great deal of confusion when taking medications. As a safety measure, ask to schedule a "brown-bag check-up" with your primary doctor or local pharmacist. A brown-bag check-up is when you gather all of your current medications and over-the-counter products into a "brown-bag" and show them to your doctor or pharmacist so he/she can look for any potential problems.

Managing Asthma

What is Asthma?

(from the National Institutes of Health)

Available online at:

http://www.nhlbi.nih.gov/health/dci/Diseases/Asthma/Asthma_WhatIs.html

Summary: This site contains information about asthma including Causes, Who Is At Risk, Signs & Symptoms, Diagnosis, Treatments, Living With Asthma, Children, Prevention, FAQs, and more Links.

Peak Flow Meters

(from the American Lung Association)

Available online at:

<http://www.lungusa.org/site/pp.asp?c=dvLUK9OoE&b=22586>

Summary: This site includes information on how to use a peak flow meter and how to understand the results.

Managing Diabetes

Diabetes

(from the National Institutes of Health)

Available online at: <http://www.nlm.nih.gov/medlineplus/diabetes.html>

Summary: This Web site from the National Institute of Health is an index to a host of other sites about diabetes. The links are organized under the following categories: Latest News, From the National Institutes of Health, Overviews, Diagnosis/Symptoms, Treatment, Prevention/Screening, Health Check Tools, Alternative Therapy, Nutrition, Coping, Disease Management, Specific Conditions, and Related Issues.

Glucose Meters & Diabetes Management

(from US Food and Drug Administration)

Available online at: <http://www.fda.gov/diabetes/glucose.html>

Summary: This Web site contains information on glucose meters and other diabetes management tests.

Making Healthy Food Choices

(From the American Diabetes Association)

Available online at:

<http://www.diabetes.org/nutrition-and-recipes/nutrition/healthyfoodchoices.jsp>

Summary: What foods are healthy? What foods are unhealthy? How do you establish a plan for eating healthy foods? What is a diabetes meal plan? This Web site from the American Diabetes Association addresses those questions and includes more information on following a healthy diet.

Reading Food Labels

(from the American Diabetes Association)

Available online at: <http://www.diabetes.org/nutrition-and-recipes/nutrition/foodlabel.jsp>

Summary: Reading labels can help you make wise food choices. Most packaged foods in the grocery store list nutrition information on the package in a section called the Nutrition Facts. The Nutrition Facts tell you the serving size and the amount of various nutrients such as total fat, saturated fat, cholesterol, sodium, and fiber per serving. This Web site includes links to the following information:

- Taking a Closer Look at the Label
- Nutrient Content Claims & Percent (%) Daily Value
- Extra Tips for People with Diabetes

Seven Principles for Controlling Your Diabetes for Life

(from the National Institutes of Health)

Available online at: <http://www.ndep.nih.gov/diabetes/control/principles.htm>

Summary: This Web site offers seven principles for controlling your diabetes and actions you can take.

Understanding Food Labels

How to Understand and Use the Nutrition Facts Label

(From the U. S. Food and Drug Administration)

Available online at: <http://www.cfsan.fda.gov/~dms/foodlab.html>

Summary: People look at food labels for different reasons. But, whatever the reason, many consumers would like to know how to use this information more effectively and easily. This Web site contains examples and information that makes it easier for you to use nutrition labels to make quick, informed food choices that contribute to a healthy diet.

Test Your Food Label Knowledge!

(From the U. S. Food and Drug Administration)

Available online at: <http://www.cfsan.fda.gov/~dms/flquiz1.html>

Summary: This Web site offers a few interesting and simple interactive activities for testing your food knowledge.

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