

Living with Limited Literacy and a Chronic Illness

by **Judy King**

Patient education is an essential component of treating people living with chronic illnesses. They receive information on exercise, nutrition, counselling, medications and community support services through many years of interacting with the health care system. This information is vital to maintaining their health and quality of life. As chronic illnesses have become a major cause of sickness and death in the world, patient education has become increasingly important (Hohn). A chronic illness, such as diabetes, asthma and arthritis, is usually defined as a condition that a person has had for at least six months.

Patient education for people living with a chronic illness usually focuses on self-management geared to reducing complications and optimizing quality of life (Long et al.). Self-management refers to the decisions and actions patients take to cope with their health problems and to improve their health (Health Canada). An important aspect of self-management is being able to identify specific symptoms and take appropriate actions to alleviate or improve them: for example, someone with diabetes learns to recognize the signs of low blood sugar and knows what to do.

Testing, testing

Many literacy and health studies have focused on establishing the levels of health literacy in different populations. Presently, researchers and health workers use two assessment tools to measure health literacy: The Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al.) and the Test of Functional Health Literacy in Adults (TOFHLA) (Parker, Baker and Nurss). The REALM is a word-recognition test containing sixty-six common medical terms that patients are asked to read aloud. The test takes two to four minutes to complete and it assumes that recognizing a medical term predicts how well a patient comprehends the term (Davis et al.). The raw scores translate into an estimate of health literacy by a grade range. The REALM is a word-recognition test and does not measure reading comprehension or interpretation. This is a major concern because both these skills are needed when using health information (Greenberg, p.72).

To address this concern, the TOFHLA was developed to assess patients' functional health literacy. It uses

actual materials from a hospital setting, such as prescription medicine bottles, appointment slips and informed-consent forms (Parker et al.). Functional health literacy is defined as "the ability of patients to complete successfully basic reading and numeracy tasks required to function adequately in the health care setting" (Williams et al.). The test consists of two parts, reading comprehension and numeracy. The test scores result in three levels of functional health literacy: (1) inadequate—is unable to read and interpret health texts, (2) marginal—has difficulty reading and interpreting health texts, and (3) adequate—can read and interpret most health texts (Nurss, p.13).

Understanding disease

Some researchers have used knowledge questionnaires to investigate the association between health literacy and understanding symptoms of specific diseases. These studies have found that people with low functional health literacy are less likely to know the specific symptoms of their disease. People with low functional health literacy also have trouble understanding laboratory results. This is true for people living with HIV/AIDS (Kalichman et al., Kalichman, Ramachandran and Catz) and high cholesterol (Parker and Jacobson).

Researchers have also investigated the relationship between health literacy, chronic illnesses and patient-education material. They found significant gaps between the readability of patient education material and the literacy levels of patients with lupus (Hearth-Holmes et al.), cancer (Merriman, Ades and Seffin), and ophthalmic problems (Ebrahimzadeh, Davalos and Lee).

Misunderstanding patient-education information can lead to harm and the need for further treatment. Health care professionals often overestimate a patient's level of reading comprehension and may think that patients don't follow instructions because they have poor motivation .

Whose perspective? Living with limited literacy

Few studies have looked at issues of literacy and health from the perspective of people living with limited literacy. Nina Parikh and her colleagues studied the relationship between shame and low functional

literacy in health care settings. Using a quantitative approach, they interviewed and assessed 202 patients of whom 67.4 per cent admitted they had reading problems. For those who admitted they had reading problems, 39.7 per cent said they felt ashamed and 67.2 per cent had not told their spouse. The shame surrounding limited literacy appears to include a social stigma and a social conditioning that has developed over the years as people have tried to hide their literacy problems (Beder). The stigma of limited literacy has also been voiced in a qualitative study that examined how adults responded to being screened for reading ability in a health care setting (Brez and Taylor).

David Baker and his research team explored the health care experiences of people with low health literacy. Themes that emerged from the interviews and focus groups included barriers that participants faced in health care settings. These barriers were: finding the hospital and locating departments; completing forms; interpreting medication instructions and appointment slips; communicating with health care professionals; and coping with the negative treatment they received when they admitted to having reading difficulties. Although many health care experiences were discussed in this study, the researchers did not ask specifically about experiences of patient education. What patient-education experiences mean to adults living with limited literacy and a chronic illness has not been investigated.

Asking the patients

With this in mind, I decided to uncover the meaning of patient-education experiences for adults with limited literacy and a chronic illness. My study attempted to explore patient education through their eyes. I wanted their voices to be heard.

I selected and interviewed fourteen adults who were attending a school board literacy program and who have a chronic illness (Kvale, Miles and Huberman) about their experiences of patient education. From these interviews, my preliminary findings indicate that participants who go back to school and improve their literacy ability feel more confident and comfortable interacting with their doctors and filling out health care forms. They felt that they could explain things better to their doctors and, because they had gone back to school, they realized that it was okay to ask health care professionals questions. As Louise, a fifty-eight-year-old woman living with arthritis and high blood pressure, states, "If I don't ask questions how will I learn?"

Participants also felt that improving the literacy skills of reading and writing had actually improved

their health status by improving their ability to understand and use patient-education information. Mekal, a fifty-year-old man living with arthritis, realized that

Being able to read has really, really affected it simply because they give you pamphlets with pictures in it, it is all words and I am sitting in the doctor's office you have a twenty-minute wait, there are magazines or there are different pamphlets there that you can pick up and read. I will pick up a pamphlet rather than a magazine and read about what's going on and try to figure out what. Before I wasn't able to sit down and pick up a pamphlet and actually read it. I could pick up the pamphlet, I would look at it and put it back but now I can sit down and read it and it makes a big difference.

Unfortunately, it seems that most patient-education information that participants receive is in written form, which is probably not the best format for people who have limited literacy. To offset the heavy reliance on written material, participants suggested that health care professionals should also use models, diagrams and pictures when explaining things to patients.

Participants also suggested that one way health care professionals could do a better job in giving patient-education information to people with limited literacy and a chronic illness is by taking more time to explain things in detail and to help people integrate this new information into their daily lives.

Communication is key

People living with limited literacy and a chronic illness face unique challenges interacting with the health care system. Health care professionals need to understand the experiences of these patients. I hope my findings will inform patient education and help health professionals find ways to communicate that optimize patient care. Improved communication could in turn reduce health care spending and improve patients' quality of life. ■

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SOURCES :

- Baker, David, Ruth Parker, Mark Williams, Kathryn Pitkins, Nina Parikh, Wendy Coates and Mwalimu Imara (1996). The health care experience of patients with low literacy. *Archives of Family Medicine*, 5, 329-334.
- Bass, Pat, John Wilson, Charles Griffith and Don Barnett (2002). Residents' ability to identify patients with poor literacy skills. *Academic Medicine*, 77, 1039-1041.
- Beder, Hal. (1991). The stigma of illiteracy. *Adult Basic Education*, 1, 67-78.
- Brez, Sharon and Maurice Taylor (1997). Assessing literacy for patient teaching: Perspectives of adults with low literacy skills. *Journal of Advanced Nursing*, 25, 1040-1047.
- Davis, Terry, Michael Crouch, Sandra Long, Robert Jackson, Pat Bates, Ronald George, and Lee Bairnsfather (1991). Rapid assessment of literacy levels in adult primary care patients. *Family Medicine*, 23, 433-436.
- Davis, Terry, Sandra Long, Robert Jackson, Elaine Mayeaux, Ronald George, Peggy Murphy, and Michael Crouch (1993). Rapid estimate of adult literacy in medicine: A shortened screening instrument. *Family Medicine*, 25, 391-395.
- Ebrahimzadeh, Hotosa, Ricardo Davalos, and Paul Lee (1997). Literacy levels of ophthalmic patient education materials. *Survey of Ophthalmology*, 42, 152-156.
- Greenberg, Daphne (2001). A critical look at health literacy. *Adult Basic Education*, 11, 67-79.
- Health Canada (1999). *Toward a Healthy Future: Second report on the health of Canadians* (Rep. No. H39-468/1999E). Ottawa, ON: Minister of Public Works and Government Services Canada.
- Hearth-Holmes, Michelene, Peggy Murphy, Terry Davis, Indrani Nandy, Celeste Elder, Louise Broadwell and Robert Wolf (1997). Literacy in patients with a chronic disease: Systemic Lupus Erythematosus and the reading level of patient education materials. *The Journal of Rheumatology*, 24, 2335-2339.
- Hohn, Marcia (1998). *Empowerment Health Education in Adult Literacy: A guide for public health and adult literacy practitioners, policy makers and funders*. Lawrence, MA: National Institute of Literacy.
- Kalichman, Seth, Eric Benotsch, Troy Suarez, Sheryl Catz, Jeff Miller and David Rompa (2000). Health literacy and health-related knowledge among persons living with HIV/AIDS. *American Journal of Preventive Medicine*, 18, 325-331.
- Kalichman, Seth, Bineetha Ramachandran and Sheryl Catz (1999). Adherence to combination antiretroviral therapies in HIV patients of low health literacy. *Journal of General Internal Medicine*, 14, 267-273.
- Kvale, Steinar (1996). *Interviews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage.
- Lorig, Kate, David Sobel, Anita Stewart, Bryan Brown, Albert Bandura, Philip Ritter, Virginia Gonzales, Diana Laurent and Halsted Holman (2002). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. *Medical Care*, 37, 5-14.
- Merriman, Betty, Terri Ades and John Seffrin (2002). Health literacy in the information age: Communicating cancer information to patients and families. *CA A Cancer Journal for Clinicians*, 52, 130-133.
- Miles, Matthew and A. Michael Huberman (1994). *Qualitative data analysis: An expanded sourcebook*, 2nd edition. Thousand Oaks, CA: Sage.
- Nurss, Joanne, Ruth Parker, and David Baker (2001). *TOFHLA: Test of functional health literacy in adults*. Snow Camp, NC: Peppercorn Books and Press, Inc.
- Osborne, Helen (2001). In other words: When you need to know: Literacy resources for health professionals. *On-Call*, 4, 34-35.
- Parikh, Nina, Ruth Parker, Joanne Nurss, David Baker and Mark Williams (1996). Shame and health literacy: The unspoken connection. *Patient Education and Counseling*, 27, 33-39.
- Parker, Ruth, David Baker and Joanne Nurss (1994). Functional health literacy of patients at two public hospitals. *Journal of General Internal Medicine*, 9, 106.
- Parker, Ruth and Terry Jacobson (2000). The role of health literacy in narrowing the treatment gap for hypercholesterolemia. *The American Journal of Managed Care*, 6, 1340-1342.
- Perrin, Burt (1998). How does literacy affect the health of Canadians? A Profile Paper. Minister of Public Works and Government Services Canada. Available online at www.hc-sc.gc.ca/hppb/phdd/literacy/literacy.html
- Williams, Mark, Ruth Parker, David Baker, Nina Parikh, Kathryn Pitkins, Wendy Coates, and Joanne Nurss (1995). Inadequate functional health literacy among patients at two public hospitals. *Journal of American Medical Association*, 274, 1677-1682.