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## **EXPERIENCES OF ADULTS WITH LITERACY BARRIERS IN THE HEALTH SYSTEM**

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This report was adapted from *Increasing Understanding of the Impact of Low Health Literacy on Chronic Diseases Prevention and Control*, researched and written by Lynn Chiarelli, July 2006.

## EXPERIENCES OF ADULTS WITH LITERACY BARRIERS IN THE HEALTH SYSTEM

Health literacy refers to a person's capacity to find, understand and use basic health information and services needed to make appropriate health decisions. Adults with limited health literacy encounter a number of barriers in finding, understanding and using health information and services. These common barriers are described in four Canadian studies that included interviews or focus groups with adults with limited literacy.

Brez, S.M., & Taylor, M. Assessing literacy for patient teaching: Perspectives of Adults with Low Literacy Skills. *Journal of Advanced Nursing*, 1997; 25: 1040-1047.

This small Ontario study included interviews with eight adults with limited literacy (4 men and 4 women). Each adult was tested using the Rapid Estimate of Adult Literacy in Medicine (REALM) tool after a recent experience as a patient in a hospital. The main purpose of the study was to better understand the response of adults with low literacy skills to having their reading ability screened to help plan for patient education.

Centre for Literacy of Quebec. Health Literacy Project. Montreal: Author. Available online at <http://www.centreforliteracy.qc.ca/health/healthlt.htm>

This three-phase research health literacy project was conducted from 1999 to 2004 through a collaboration of the Centre for Literacy of Quebec and the McGill University Health Centre (MUHC). Phase 1 was a needs assessment of the health and information needs of the "hard-to-reach" patients. ("Hard-to-reach" referred to patients facing literacy, language and cultural barriers, and those who have difficulties processing health information because of physical or cognitive disabilities. It is no longer used because it said more about the health care providers than the patients.) The project included 66 interviews and 7 focus groups (total of 45 participants) with patients in day treatment, family members, support staff and health care professionals from the dialysis unit, the oncology/ hematology clinic and the pre-operative clinic.

Gillis, D., & Quigley, A. (2003). *Taking off the blindfold: Seeing how literacy affects health*. Retrieved February 9, 2004, from St. Francis Xavier University, Department of Human Nutrition Web site: <http://www.nald.ca/healthliteracystfx/links.htm>

In 2004, a participatory research project was conducted in the Guysborough-Antigonish health region of Nova Scotia. In total, 130 people were interviewed as part of the study. This included 25 adults enrolled in adult learning programs, 21 adults from the hospital diabetes outpatient clinic and community-based health agencies. Participants included four Acadians, five Mi'kmaq and four African Nova Scotians.

King, J. *The Meaning of Patient Education Experiences for Adults with Limited Literacy and Chronic Illnesses*. Draft Dissertation, December 23, 2005. University of Ottawa, Faculty of Education, Thesis Supervisor, Dr. Maurice Taylor.

The researcher interviewed 14 adults with a chronic illness who were attending a school board literacy program in 2004. The participants were interviewed about receiving health information from health care providers directed towards managing their chronic illnesses, including asthma, arthritis, diabetes and high blood pressure.

Each of the above studies found that participants faced significant barriers when they had to interact with individual health care providers or with the health care system.

### **INTERACTING WITH INDIVIDUAL HEALTH CARE PROVIDERS**

Participants expressed feelings of powerlessness in interacting with health care providers including feelings of shame, stigma and the fear of being discovered as having limited literacy. Such a discovery could lead to a breakdown in the trust relationship between patient and health care provider. Participants expressed concerns that they did not want to be singled out or treated differently due to their literacy abilities.

Barriers also included the use of written information that was not useful to the participants because of difficulty with the vocabulary used. These difficulties could arise because of the use of medical terms, the level of reading required, or unfamiliarity with the language of the material was not in their first language. Also, written information did not often discuss issues that were most important to the patients. Participants said that their primary health information needs concerned issues related to daily living such as diet, and exercise.

Within verbal interactions, barriers occurred due to unfamiliarity with the medical jargon used by health care professionals. As well, participants noted that often language and culture were not taken into consideration when health care providers gave advice.

Participants recognized that they need to be responsible for their own health but were frustrated in their ability to take on this responsibility when they did not receive appropriate health information to do so. There appeared to be differences in expectations between what information health providers felt the participants needed, and what information participants themselves felt they needed and hoped to obtain from the health care provider.

Often the information participants were given was not precise enough to allow the formulation of a concrete and individualized plan. For example, participants who had diabetes were told to exercise more, but were not given specific information about what specific exercise to do.

### **INTERACTING WITH THE HEALTH CARE SYSTEM**

Within the larger health care system, time presented a major barrier. Participants noted that there was not enough time in patient-provider encounters to build trust and exchange information. As well, chronic disease management information often was given only once, due to time constraints, while the participants expressed a need to have health information repeated a number of times on different occasions.

As well, participants noted that there were not enough translators available in health care facilities necessitating reliance on family and friends, who may have their own

language and literacy limitations. Reliance on family members also resulted in role reversal for many in terms of the parent-child relationship.

The advent of more and more health information being web-based and no longer being produced in a paper format has led to a digital divide. Many participants mentioned that computers are a barrier for them to receive health information; they do not have the literacy skills to use a computer and often if they did have the skills they can not afford a computer and internet access in their home and have no other access to a computer.

Due to fragmentation in the health care system, they felt like they had great difficulty understanding the workings of the health system. They often were not aware of or told of other health or social services and available health information in their community that could be helpful to managing their health problems. Many participants articulated feelings of general social isolation. Participants expressed a need for social support and affordable social services.

### **FOCUS GROUP-MARCH 2006- SUGGESTIONS FOR FUTURE RESEARCH**

Within this project, a focus group was conducted to verify some of these previous findings from the Canadian research studies. The focus group participants were adult learners who were members of the Learners' Advisory Network of the Movement for Canadian Literacy. They were asked about how future studies could be carried out to gather Canadian's views on strategies towards chronic disease prevention and control that could be helpful for people living with limited literacy.

The focus group members were not surprised at any of the findings of the previous studies. Many had similar health experiences and had encountered similar barriers. The group acknowledged that every person is different and that different ways are needed to get input. They provided some guiding principles to use when conducting further studies in this area.

Learners' time and expertise needs to be recognized and valued by providing honoraria for their participation. Interviews need to be relatively short, one to two hours. Probably the best way to recruit participants for a study is to go through established literacy networks in existence, such as the Learner's Action Network (LAN) of the Movement for Canadian Literacy (MCL). These literacy organizations would act as intermediaries.

Potential participants need to be contacted by someone they trust from their literacy programs. Learners might not be comfortable talking to government officials and might be frightened by a call from a health care professional or organization. For some participants, a phone interview would be the most comfortable. Others would prefer a face-to-face interview. Different approaches need to be considered to reach adults who are not involved in literacy programs (e.g., through familiar environments such as malls, work, schools, community health centres.)

## **DISEASE CONTROL AND PREVENTION MESSAGES**

Participants in the focus group and in the studies mentioned that they get their health information from a variety of sources, including radio, television, in the workplace, in literacy classrooms and through their children's schools. In fact their children's schools might be the perfect place to discuss chronic disease prevention, because all members of the family could be involved. It was suggested that any health message need to be repeated again and again, using a variety of methods, television, radio and print advertisements.

The participants in the focus group emphasized that regardless of the approach taken to deliver health information, it is important not to lose sight of the big picture. For example, a person with limited literacy may understand that they need to eat fresh fruit everyday but due to their financial situation cannot afford fresh fruit or they live in an area where fresh food is not available at an affordable price (e.g., a Northern or remote community).

## **CONCLUSIONS**

Overall, the messages from the research and the focus group indicated that there are significant barriers to receiving health information, including information about chronic disease prevention and control. Health information strategies or initiatives directed towards chronic disease prevention or control need to address these barriers. Having limited literacy does not occur in isolation from the other determinants of health. People need to have a safe place to live, a job that provides a decent income, and access to health care service such as a family doctor. People living with limited literacy and health problems have multifaceted and complex lives in which just one part is dealing with their health.