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B. Allan Quigley

St. Francis Xavier University

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“What Would You Do In My Place?” Outcomes of a Collaborative Health Literacy Research Study in Rural Nova Scotia

B. Allan Quigley,

St. Francis Xavier University

Abstract: The 1994 and 2000 *International Adult Literacy Surveys* found that 43% of Canada’s adult population is affected by low literacy skills, with 22% of these adults experiencing severe literacy problems. The highest rates of low-literacy skills have consistently been found in the Atlantic provinces. However, what these studies do not reveal are the life-and-death health issues that often lie beneath the statistics. To the question: “What would *you* do in my place?” posed to us by an unemployed fish plant worker with low literacy skills and severe health issues living in an isolated Nova Scotia community, such surveys provide no answers. This two-year study investigated: 1) factors that influence ways less literate adults in NE Nova Scotia access and act upon health information and services, and 2) strategies for change that could build on capacities for achieving health.

Becoming Aware of a Major Issue

The positive correlation between low-literacy and poor health is well established in the health education/health promotion literature. As Rudd observed: “We, in public health, have long known that education and health are linked. Decades of research indicate that people with lower educational achievement . . . have higher death rates for chronic and communicable diseases than do people with higher educational achievement” (Soricone & Santos, 2002. p. 2; and see Rudd, 2002). Similarly, the *Second Report on the Health of Canadians* (Federal, Provincial...,1999) reveals that those with low literacy levels not only suffer high unemployment rates and low incomes, but also live with poorer health and die earlier than those with higher levels of education. In part, this is because adults with limited literacy frequently have difficulty accessing and making use of health information/health services (e.g., Perrin, 1998) and, as seen in the *Second Report*, socio-economic and cultural issues are also central to health literacy. In addition, it has long been known that adults with limited literacy often feel alienated within the dominant culture (Quigley, 1997), have low participation rates in formal education (Belanger & Tuijnman, 1997), and often feel alienated from traditional social institutions (Quigley & Arrowsmith, 1997). This 2-year study sought to investigate low literacy acts as a determinant of health, and explore strategies that could be implemented at both a practice and policy level to address such health literacy issues. Our two research questions were: What are the factors that influence the ways less literate adults living in North East Nova Scotia access and act upon health information and services, and what strategies for change will build on existing capacities for achieving health?”

Research Perspective and Context of the Study

Besides being among the provinces with the highest rates of low-literacy in Canada, (e.g., Calamai, 1987; OECD, 1994, 2000), Nova Scotia has higher rates of chronic disease and more socio-economic risk factors due to limited education and income than any other province (GPI, Atlantic, 2002). This was noted in our initial report at the 2000 CASAE conference (Quigley & Gillis, 2000). At that time, our multidisciplinary research team from the disciplines of Adult education, Human Nutrition, and Nursing at StFX had just begun partnering with 5 community literacy and health organizations in two—later three—rural counties; namely, Antigonish County, Richmond County (in Cape Breton), and Guysborough County. Supported by a SSRHC-Valuing Literacy Partnership Development grant, we hosted two community meetings, one in Antigonish, one in Richmond county, where we received input from a wide range of health and literacy

personnel, as well as from adult literacy learners in ABE programs. This input assisted us as we developed our full SSHRC proposal, and we submitted it in January, 2001. This first step also helped us build an Advisory Committee of experienced health and literacy personnel that stayed with the project through the coming two year period. We have since explored factors that influence the ways less literate adults living in NE Nova Scotia access and act upon health information and services. To do this, we have: 1) used a 3-stage interview model which encouraged each interviewee and focus group participant to begin with the situation at hand, reflect on their experience and make meaning of it, and conclude with concrete strategies for change; 3) and we then developed and circulated a plain language report (Gillis, Quigley, McIsaac, Shively, 2004) for a Roundtable Discussion on the many strategy recommendations made by the study participants. The Roundtable brought together some 50 people, including a number of the study participants and institutional policy-makers from health and literacy in Nova Scotia, the Minister of Health, and officials from the Department of Education, and interested stakeholders in the province. This was day-long session was held February, 2004 at St Francis Xavier University. Due to inclement weather that day, a second Roundtable discussion was held at Port Hawkesbury, Richmond County, Cape Breton. The recommended strategies in the Roundtable Report were discussed and prioritized at the Antigonish Roundtable, and some new ones were added as well. The second Roundtable led to further prioritizing of the reports' strategies, and a few new strategies were added. The second Roundtable meeting allowed for validation since one community was reviewing and reacting to the prioritizing of the first.

The final SSHRC report is being developed at the time of writing, whereby all of the findings and the prioritized strategies will be taken forward to the Ministers of Health and Education. In addition, a community-based Health Literacy Advocacy group is forming to lobby for the recommended changes, and to build on further health literacy practice and policy possibilities.

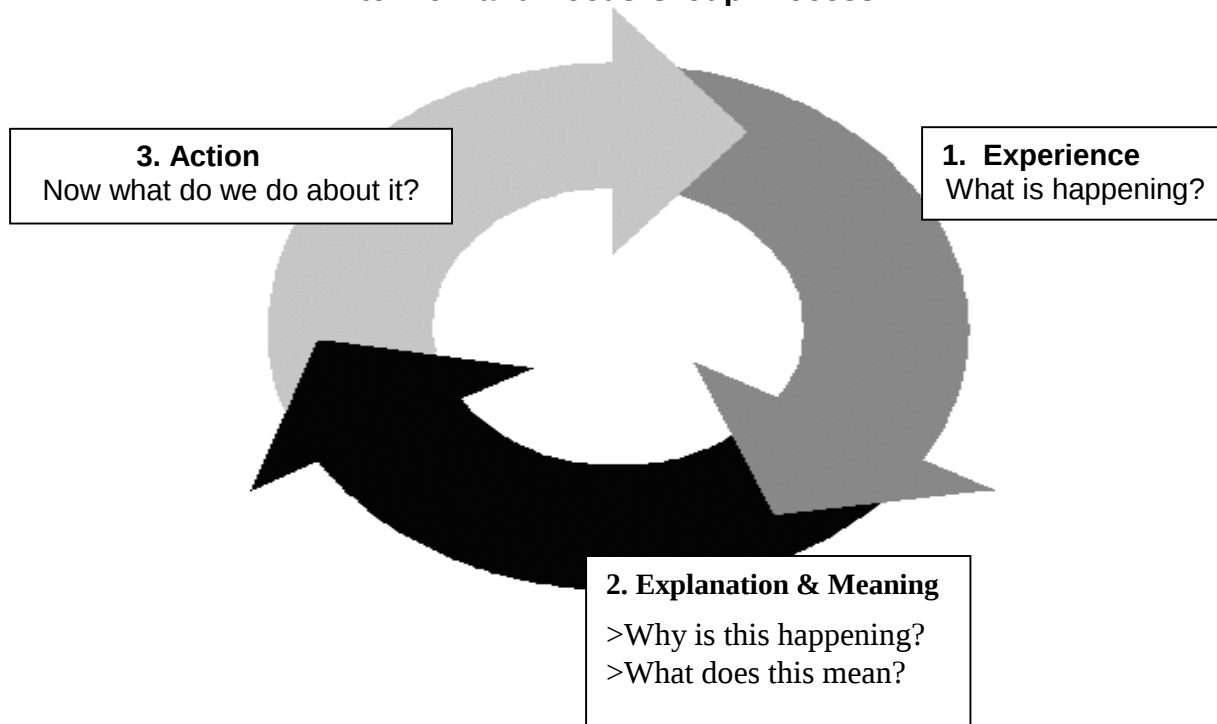
Research Design and Methods Used

Interview Participants: With their informed consent, we interviewed 25 adults enrolled in adult learning programs and 21 adults with limited literacy not enrolled in adult learning programs (N = 46) using a semi-structured interview protocol. We recruited non-participants through community-based agencies. Of the total 46 participants in these two groups, 15 were male and 31 were female; four were of Acadian descent and spoke French as their first language; five were Mi'kmaq; and four were African Nova Scotian. Their ages ranged from 18 to over 55, and they had grade levels ranging from grade one to grade 12. All of the participants had struggled with "getting an education," and spoke from the experience of limited literacy.

In addition, we held seven focus groups involving 64 health and literacy professionals (N=64) who were working with adults limited in literacy. As well, we interviewed 20 community leaders as our key informants (N=20). We audio taped and later transcribed all 130 of the interviews, then analyzed the data using ATLAS.ti software.

Interview Process: Ethnographic methodologies were used throughout. We drew on an interview process of reflective learning stages (Labonte & Feather, 1996). In our case, three stages for both the personal interviews and the focus group discussions were used. Participants were first asked to discuss their life experiences relevant to the study (*description*), including, "What does 'literacy' mean to you?" and "What does health mean to you?" They were then asked to analyze their experiences (*explain*) and reflect on the meaning (*meaning-making*) of these experiences; then we asked them to suggest actions for change (*strategies*) at the personal, systemic, and policy levels of health provision and literacy programs, as shown in the figure below:

Interview and Focus Group Process



As noted, the team used Atlas.ti qualitative software for the data analysis. It was highly effective for the task of analyzing qualitative data. For the Roundtable Report, we focused on the participants' comments on strategies for change. Further analyses of the data will be conducted over the coming months.

Findings and Recommendations

First, we have found that developing partnerships with community-based health/literacy practice organizations has provided a remarkably strong foundation for this collaborative research, and for future policy/practice change. We also found that initiating collaboration and dialogue across sectors often requires practitioners to expand their perspectives—perspectives which tend to be filtered through the familiar lenses and language of their respective professions. Through the analyses of the interviews/focus group data, we developed in excess of 200 data codes around subjects, topics and expressed views. We then identified a number of key determinants of health that emerged and how they are affected by—and linked to—low literacy. The broad determinants headings included: gender, culture, institutions, personal health practices, community inhibitors or enablers, and perceptions of well-being. It can be noted that some of the salient findings included how the low self-esteem of less-literate adults in unfamiliar cultural contexts, for instance, in hospital and medical settings, can be virtually “paralyzing.” In such settings, some reported they became intimidated by health systems and it was obvious they benefited little by such experiences. By contrast, we found there is a “bridging” role being conducted by community pharmacists and nutritionists among some less-literate adults in our groups. Interestingly, pharmacists and nutritionists often “interpreted” and advised on medications and medical conditions well after the visit to the hospital or health care giver. As this was a study based on rural Nova Scotia, several major themes emerged on health literacy in

the study's rural settings, including: issues of social isolation; lack of transportation; limited opportunities and/or decreased access to each of employment, recreation, health care, education opportunities, and social support services all came forward. Participants also said that small communities are often close and supportive, which can lessen the negative impact of limited literacy on health. As one person said, "There's people that can help you." However, there was also a tendency for less-literate participants to assume a sense of general "well-being" based on context. We heard, for instance, that people were "very healthy" and had "good literacy skills" relative to those in their family, community, or area. This, despite obvious poor health, low literacy skills, and a state of deep poverty. While the perceived state of one's well being is typically influenced by the norms of one's lived circumstances, in many of the cases, the circumstance of participants' health and literacy were obviously far worse, and more deleterious, than participants were perceiving. Following the analyses of the data collected, we had over 100 strategies and suggestions from the interview participants. For purposes of the plain language Roundtable Report, they were coded by interview group, organized by the Determinants of Health mentioned earlier, and structured so Roundtable participants could see where action *might* arise on each of the strategies from: the Policy Level (local, provincial, and/or federal level), the Program Level (literacy, health, and social programs, as well as departmental and community-based programs), and/or from the Practice Level (how service providers work with the people they serve). Many of the strategies fell into more than one of these categories for action. Having organized the strategies into a working report for Roundtable Discussion(s), they were then prioritized by the participants. In addition, they worked to suggest who needs to be involved on each strategy and they named a timeframe for action on each strategy.

More specifically, on the theme of "Value and support the important role of community-based organizations and services in fostering health and literacy," the strategies were prioritized as follows: 1) Identify those community organizations that have an impact on health and literacy; promote awareness of the health promotion role of these organizations among health care professionals; 2) Form an Association of Community Based Organizations so that they speak with a louder voice for lobbying purposes; develop an Association Listserv to share information; 3) Commit to learning more about and supporting one other's local organization each year, attend their functions, tell people about them; 3) Encourage more women to become involved in politics. To the theme of: "Provide sustained funding for more flexible literacy programming to meet the life and learning needs of more people," the strategies were prioritized as: 1) Clarify, highlight and commit to the importance of literacy/health/employability in a broader context: adult literacy, early childhood, school-based supports, learning approaches 2) Commit to knowing the "why"— why our school system is not meeting the needs of so many, 3) Start a "Prevention Revolution."

To the theme of "Develop health and literacy promotion strategies that address the impact of a rural environment on health and literacy," the prioritized strategies were: 1) Bring people together from various community organizations, 2) Develop community information sessions with trusted people, 3) Provide easier accessibility, 4) Develop a transportation system, 5) Policy: look at government departments, 6) Provide public Service announcements on national TV and local radio. And, to the theme of: "Create more opportunities for public transportation in rural areas to access education and health services," recommendations were prioritized as: 1) Implement a "late bus" concept to school board to allow student participation, and implement community shuttle service and share-a-ride. Further themes included: "Create health drop-in centers where individuals can access information and find someone to talk to about health issues," provide 'health-mobiles,' similar to mobile libraries, that go out to rural areas with information and someone to talk to," and "Increase

awareness of literacy issues among service providers by: Including literacy issues in curriculum for health care providers, teachers, social workers, 2) Identifying champions in faculty, 3) Sending letters to Ministers of Health, Education, Community Services, 4) Increasing community awareness by advocating for action, demanding appropriate services, providing ongoing community awards, 5) Providing in-service training and orientation in literacy/health by taking research project presentation on the road to other groups, communities, and use theatre group to increase public awareness, and 6) Identifying champions responsible for providing health/literacy component.

These priorities were confirmed by the Richmond County Roundtable and their additions included: “Increase awareness of literacy as a determinant of health and well-being,” “address behavior problems,” “Respect people’s innate abilities and life experiences when determining their ‘employability,’” “Simplify explanations and instructions,” “Learn and use principles of plain language,” “Make interpreters available where the first language is not English,” and “Increase networking among service providers.” Their additional suggestions included: 1) Coordination of services is needed; many agencies/organizations are working with the same clients in the community, 2) Use the Health Literacy Project Report, *Taking off the Blindfold* to raise awareness and influence decision making, 3) Redirect funding to prevention and promotion rather than concentrating on chronic care.

Next Steps & Implications

With the help of the two Roundtable Discussions, the strategies for change that we heard from the research participants are now prioritized with timelines and suggested agencies to take the lead. Our final report is being prepared and it will be submitted to SSHRC, and to the Ministers of Health and Education for Nova Scotia. Further, a community Health Literacy Advocacy is forming with practitioners and interested stakeholders from across Northern Nova Scotia. This Advocacy Committee will seek to have strategies implemented at the local, regional, and provincial levels. Beyond this point, the data will be further analyzed on other health literacy topics as well in the coming months.

Since this study is among the first in Canada to investigate literacy as a determinant of health, and the first to do so in rural settings using in-depth interviews, the outcomes may well initiate further research based on our findings and the methodologies and analysis software we used. Above all, this study has brought the two fields of literacy and health much closer together and promises to build a foundation for future research and practice/policy action. The issue of health literacy is now in the public and the political discourse for Nova Scotia and both our finding and our research-to-advocacy model may well prove useful to others in Canada and beyond.

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