LITERACY AND HEALTH: Prescription for progress

Critical Issues in Literacy and Health



Irving Rootman, Ph.D.

Professor and Michael Smith Foundation for Health Research Distinguished Scholar, University of Victoria

Introduction

As a relative newcomer to the field of literacy and health I was surprised at the number of issues facing the field. Some of the critical issues that I have become aware of include: **Definitions, Measurement, Culture, Language, Evaluation and Research**.

Of course, my selection of issues reflect my own perspectives as a researcher interested in policy and practice, but hopefully presentation of them in this "think piece" will at least stimulate discussion at the Institute and perhaps suggest other issues of concern to participants.

Definitions

There are a number of definitions of "Literacy" and "Health Literacy" in use. Some of the common definitions of "Literacy" include:

"the ability to decode and comprehend written language at a rudimentary level -- that is, the ability to say written words corresponding to ordinary oral discourse and to understand them"

(Kaestle et. al., 1993).

"ability to understand and employ printed information in daily activities—at home, at work and in the community— to achieve one's goals and develop one's knowledge and potential"

(International Adult Literacy Survey, 1995).

"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"

(US National Literacy Act, 1991)

"a complex set of abilities to understand and use the dominant symbol systems of a culture for personal and community development"

(Centre for Literacy of Quebec, 2000).

These definitions represent different perspectives on the concept of literacy. The first

suggests a narrow technical view, limited to understanding the written word; the second, although also limited to the written word, goes beyond understanding to using the information in daily life; the third suggests that it includes speaking and writing as well as reading although it is explicitly limited to English; and the final definition suggests that it is not necessarily limited to English and that the abilities might be used for community as well as individual purposes.

Questions for us are: Which definition do we prefer and why?

Similar questions confront us when we consider definitions of "health literacy". Some of the definitions in use are:

- 1 "ability to read and comprehend prescription bottles, appointment slips, and other essential health-related materials" (Ad Hoc Committee on Health Literacy, 1999)
- 2 "the capacity to obtain, interpret and understand basic health information and services and the competence to use such information and services to enhance health" (US Department of Health and Human Services, 2000)
- "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health" (Kickbusch and Nutbeam, 1998)

Again, they go from narrow to broad, the first limiting itself to understanding written material within a health care context, and the second and third including other skills within a broader context. In addition to addressing the questions above, we may want to consider whether or not "health literacy" is a separate and distinct type of literacy or simply "literacy" within the health context?

Measurement

Related to the issue of definition is the issue of measurement. If we can't measure whatever definitions we chose, how will we be able to monitor and evaluate the effectiveness of what we do to address health problems related to literacy or health literacy? Unfortunately, although there has been some progress made in the past few years, we still have a long way to go before we have satisfactory measures of both literacy and health literacy.

With regard to the former, the International Adult Literacy Survey is the main source of measures of literacy in the general population in Canada and other countries, which allows us to make some useful comparisons. However, the survey measures only a limited number of components of literacy (reading and writing), and misses others (e.g. listening and speaking). The latter are critical in the health care context, so how can we proceed to evaluate literacy efforts in that context without such measures?

With regard to practice and policy, the differences suggest that we need to take culture into account in developing both our professional practices and policies. But how do we do so in a health system in which prejudice and ignorance often get in the way of open-mindedness and cultural sensitivity?

With regard to health literacy, again, there has been some progress through the development of measures such as the Rapid Estimate of Adult Literacy in Medicine (REALM) and Test of Functional Health Literacy in Adults (TOFHLA) tests. Once again, these tests measure only a limited range of capacities associated with health literacy and with the exception of the TOHFLA-Spanish version, are in English only. So the questions for us are how do we go about developing more adequate measures of literacy and health literacy and how do we go about our work in the meantime without having such measures?

Culture

A third issue is the issue of culture. It is clear that culture has a substantial impact on the relationship between literacy and health. Among other things, people from different cultural groups view both literacy and health differently, have different life experiences which affect both their literacy and their health and are exposed to different kinds of opportunities for improving both their literacy and their health. These differences have important implications for research, practice and policy in literacy and health.

With regard to research, they suggest that a "participatory research" approach might be most appropriate for the study of the relationship between literacy and health. They also suggest that it is important to study how literacy is perceived in different cultural groups, how culture affects literacy and the extent to which different approaches to improve literacy work in different cultural groups. With regard to practice and policy, the differences suggest that we need to take culture into account in developing both our professional practices and policies. But how do we do so in a health system in which prejudice and ignorance often get in the way of open-mindedness and cultural sensitivity?

Language

A fourth related issue is language which often gets mixed up with literacy. Health Canada has recently released a report on *Language Barriers to Health Care* (Bowen, 2001). Among other things, this report suggests that "in many cases, language rather than cultural beliefs may be the most significant barrier to initial contact with health services" (Bowen, p. vi). It also suggests that there appear to be significant direct and indirect health impacts of language barriers on health, but that these relationships are affected by other variables including socio-economic status and health literacy. So the questions for us are how do we disentangle the effects of language, culture, socioeconomic status and literacy on health, and what are the implications for practices and policies?

Evaluation

This brings me to the fifth issue, namely evaluation. Although Canada has a strong international reputation with respect to literacy and health interventions, partly because

of the work of the National Literacy and Health Program, the amount of rigorous evaluation of such efforts has been minimal. The Canadian Literacy and Health Research Program is attempting to address this deficit, but has a long way to go before we can be satisfied that indeed, our efforts to improve health through literacy are effective and efficient. So the question for the Institute is, how do we enhance the climate and infrastructure for evaluation of literacy and health efforts in Canada?

"...how do we build the relationships between researchers, practitioners and policymakers needed to carry out more relevant and useful research?"

Research

Finally, as suggested in the discussion of culture and language, we clearly need to do more research on literacy and health. Again, the Canadian Literacy and Health Research Program moves us some way in that direction through the identification of priorities for research (see http://www.nlhp.cpha.ca/clhrp/wrkshp e/cover.htm). However, we still have some distance to go to develop the kind of research which will be truly helpful to practitioners and policymakers interested in improving health through literacy. Thus, a question for the Institute is: how do we build the relationships between researchers, practitioners and policymakers needed to carry out more relevant and useful research?

Conclusion

As mentioned, this is a somewhat biased view of the issues in the field of literacy and health. Nevertheless I hope that it will help participants at the Institute identify and express their own biases so that we can have a productive discussion leading to better understanding, if not consensus, on the issues that prevent us from moving forward in the field of literacy and health.

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Irving Rootman is a Professor in the Faculty of Human and Social Development at the University of Victoria and a Michael Smith Foundation for Health Research Distinguished Scholar. His main research area is literacy and health. He has worked in the field of Health Promotion for more than 25 years, first at the federal level in the Health Promotion Directorate and then at the University of Toronto as Director of the Centre for Health Promotion.

Irving Rootman also spoke about the development of the National Literacy and Health Research Program supported by the Social Sciences and Humanities Research Council. He summarized what had been done to date and outlined plans for the future, including ways of involving interested participants in its further development.

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