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ABSTRACT

A research study examined the relationship between illiteracy and health. The study used the following methods for gathering information: review of health status data from major Canadian health status surveys; multidisciplinary literature review across areas including medicine, health education, development, literacy, education, poverty, and socioeconomic status; questionnaire sent to health and literacy organizations across Ontario; three case studies at different sites in Ontario; and key informant interviews. The major finding was that illiteracy had a major, negative impact on health. This finding was consistent across a wide variety of measures of health status, including overall levels of mortality and morbidity, self-rated health, activity limitation, infant development, accidents, and a wide range of diseases. Evidence suggested that illiteracy leads to poorer health through a combination of both direct and indirect intervening variables. Potential solutions are grouped under the headings of social policy action, heightened awareness within the health community, working together with the community, provision of health information in nonwritten forms, and simplification of written information about health. (Appendixes include 93 references and observations of community organizations about health and literacy problems.) (YLB)

Literacy and Health Project

PHASE ONE

Making the World Healthier and Safer for People Who Can't Read

Research Report

ONTARIO PUBLIC HEALTH ASSOCIATION
L'ASSOCIATION ONTARIENNE DE LA SANTÉ PUBLIQUE

frontier college frontiers

LITERACY AND HEALTH - MAKING THE CONNECTION

The Research Report of the Literacy and Health Project, Phase One: Making the World Healthier and Safer for People Who Can't Read

by

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15 November 1989

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EXECUTIVE SUMMARY

Background

Virtually one-quarter of Canadian adults are functionally illiterate.

What is the relationship between literacy and health? To what extent are people with limited reading ability excluded from access to health and safety information? What is being done now and what should be done in the future to enable people with limited literacy skills to live healthier and safer lives?

The purpose of this research study was to explore issues such as these. The research formed one component of the *Literacy and Health Project, Phase One: Making the World Healthier and Safer for People Who Can't Read*, jointly sponsored by the Ontario Public Health Association and Frontier College.

Methods used in the study included: a review of health status data from major health status surveys; a comprehensive, multi-disciplinary review of the literature, considering both published and unpublished information; a brief questionnaire to health and literacy organizations across Ontario, three cases studies at different sites in the province, and a number of key informant interviews.

To the best of our knowledge, our study represents the most comprehensive examination to date, in Canada and elsewhere, of the relationship between literacy and health.

Literacy and Health Status

The evidence is clear and unambiguous: illiteracy has a major, negative impact on health. This is the major finding of our study.

This finding is consistent across a wide variety of measures of health status, including: overall levels of mortality and morbidity, self-rated health, activity limitation, infant development, accidents, and a wide range of diseases including cardiovascular disease, rheumatoid arthritis, diabetes, cancer, hypertension, and many others. For example, one research team reported that: "of the 23 health conditions reported by more than 1 percent of the population, 19 differed significantly in reported frequencies according to formal educational level." Furthermore, a variety of epidemiological and multi-variate studies have indicated that the effects of literacy are independent of other variables and potential associations, such as age and income and reverse causality from health to literacy.

Nature of the Impact - The Intervening Variables

How does illiteracy lead to poorer health? The evidence suggests that this takes place through a combination of both direct and especially indirect intervening variables.

Direct Impacts

The literature provided very limited informacion about the direct effects of literacy on health. However, the responses of community health and literacy workers to our questionnaire, as well as the case studies we conducted, identified numerous examples of the following types of health problems, often severe enough to require hospitalization, directly due to illiteracy:

* Not following medical directions,
* Incorrect use of medications,
* Errors in administration of infant formula, and
* Safety risks, particularly at the workplace.

Indirect Impacts

Health problems such as those indicated above, resulting directly from an inability to read, are significant and dramatic. However, a striking finding from our research is that the major impact of illiteracy on health status occurs indirectly.

The major indirect means we have identified through which illiteracy leads to poor health include:

* Poor lifestyle practices,
* Poverty,
* Stress and low self-esteem,
* Dangerous work environments,
* Lack of access to health information, and
* Lack of use or inappropriate use of medical and health services.

Summary

Three underlying themes emerge from a consideration of the direct and indirect intervening variables through which illiteracy affect health status: lack of knowledge, lack of resources, and lack of empowerment and control.

Awareness of the Problems Resulting From Illiteracy

Many people within the public health and the literacy communities are aware of the potential impact of illiteracy on health. However, even these people feel isolated and identified the need for training and other forms of assistance, in order to enable them to recognize when illiteracy may be a factor and how to respond appropriately.

But many others - over 20 percent of those who responded to the questionnaire, and probably many of the others who chose not to - indicated that they are not aware of the relationship if any, between literacy and health. Some persons denied outright that illiteracy could result in any health problems! And it appears that health workers, like other Canadians, cannot comprehend the full extent of illiteracy in our society.

Potential Solutions

These findings have major implications for health policy, for the delivery of medical and health services, for health education and promotion, and for future research priorities. For example, medical economists have indicated that: "each additional dollar spent on education reduces mortality more than each additional dollar spent on medical care".

Potential solutions, identified both by our own data as well as from the literature, can be grouped as follows:

* Social policy level action, including:
  - A societal commitment to the reduction of health inequities,
  - A commitment by the health and medical communities to the reduction of health inequities,
  - Improved living conditions for people living in poverty,
  - Reduction of illiteracy by teaching people to read,
  - Commitment to greater safety at the workplace.

* Heightened awareness within the health community.

* Working together with the community.

* Provision of health information other than via the written word.

* Simplifying written information about health.

Priorities for Research and Evaluation

Additional research could tell us more about the specific mechanisms by which health problems may result from illiteracy. Much of the existing information is correlational in nature. However, it is already quite clear that illiteracy does result in significant health problems.

Consequently, a higher priority for additional research would be to focus on the best means of avoiding and minimizing these problems. There is a need for program evaluation, to document changes in health status following the acquisition of literacy skills, as well as to test the effectiveness of various intervention strategies.

Furthermore, the evidence suggests that social factors, such as illiteracy, have a greater impact on health status than medical interventions. Research priorities should be revised to reflect this reality.

Conclusion

This research study documents clearly that there is a problem. Illiteracy does have a major impact on health, through both direct and indirect intervening mechanisms. The health of people with limited literacy skills is worse as a result. The research supports the need for action to combat the health problems which result from illiteracy.

1. INTRODUCTION

The Literacy and Health Project, Phase One: Making the World Healthier and Safer for People Who Can't Read,[1] was jointly initiated by the Ontario Public Health Association and Frontier College because of a belief that illiteracy is dangerous. Why? As the original proposal for the project stated:

> "Many of our fellow citizens are either unable or require assistance to read, write and use numbers so that they can meet the literacy demands of today's society. One of [these demands] is to receive and understand information related to health."

Thus it follows that people who cannot read, write and use numbers would have difficulty receiving health information available in written form, understanding directions for medications, and reading safety directions. It further follows that illiteracy can be dangerous - to the extent that it precludes access to health and safety information. Anecdotal evidence bears this out. For example, learners in Frontier College's literacy programs have given examples of health dangers which they have faced in being unable to tell the difference between "no-name" cooking and motor oils.

Recognizing this situation, the goals of the Literacy and Health Project were threefold:

* To identify major health issues for people with low literacy skills;

* To establish a network of organizations and individuals representing a variety of disciplines and interest areas (including literacy, health, social service, business, government); and

* To develop recommendations with accompanying strategies to deal with the literacy and health relationship.

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[1]The report of the project (a charge may apply) is available from: Literacy and Health Project, Ontario Public Health Association, 468 Queen Street East, Suite 202, Toronto, Ontario M5A 1T7.

The Research Study

Until now, any evidence about the health dangers of illiteracy has been very limited. In order to develop an effective action strategy to combat the problem and to demonstrate the rationale for action, it is first necessary to document and describe the extent of the impact of illiteracy on health and the nature of the health problems which result.

Thus, a major component of the literacy and health project included a research study to document the relationship between illiteracy and health. This report describes and discusses the findings and implications of the research study.

The major purpose of the research was to explore questions such as:

* Do people with limited literacy skills have poorer health as a result? In what ways? To what extent? Why?

* How do people with limited reading ability obtain their information about health? How appropriate are health and medical services for them? How aware are health and medical workers of health problems associated with illiteracy?

* What are potential <u>solutions</u> and means of addressing these problems?

2. METHOD

This study used the following methods of gathering information.

a. Review of Health Status Data

We reviewed relevant statistical data from major Canadian health status surveys,[2] as well as reports and secondary analyses based upon these data sources.[3] These surveys, in addition to collecting information about various measures of health, also identified the education levels of respondents. We found a wealth of information contained in these data. To date, however, there has been minimal consideration of the implications of these data for the relationship between literacy and health, even by the sponsors of these surveys, and few analyses have focused on literacy.

b. Literature Review

We conducted an extensive, multidisciplinary literature review of published and unpublished information from Canada and abroad, across areas including: medicine, health education, development, literacy, education, poverty, and socio-economic status. The papers and documents which we reviewed are discussed in the text as appropriate and listed in the References Section.

We uncovered considerable relevant information, from a variety of sources. This information, however, was scattered across many different places, with little systematic attention to the relationship between health and literacy. Much of the relevant information which we did discover was not specifically described as dealing with health and literacy. The literature contained few reports of primary

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[2]These include: Canada's Health Promotion Survey (Health and Welfare, 1988), the General Social Survey ((Statistics Canada, 1987), the Canada Health Survey (Statistics Canada, 1981), the Quebec Health Survey (e.g. Emond & Guyon, 1988), the Ontario Child Health Study (e.g. Ontario Ministry of Community and Social Services, 1986a and 1986b), Physical Activity Patterns in Ontario III (Ontario Ministry of Tourism & Recreation, 1986). Many of these surveys have been briefly reviewed in a special publication of Statistics Canada (undated).

[3]For example: Adams, 1988; Boyle, 1988; Boyle et al., 1987; Hirdes et al., undated; Wilkins, 1988a; Wilkins, 1988b; Wilkins and Adams, 1987.

data gathering other than via health status surveys, although there were some reviews summarizing evidence from a number of different sources.

To the best of our knowledge, our study represents the most comprehensive examination to date, in Canada and elsewhere, of the relationship between literacy and health.

c. Observations of Community Organizations about Health and Literacy Problems

A brief questionnaire in letter format (see Appendix A-1) was sent to a total of 368 contacts, including public health units, community health centres, community literacy groups and others in Ontario, asking them to comment on five basic questions:

> *Are you aware of health problems that are related to illiteracy?*
>
> *If so, what specific problems have you encountered?*
>
> *How is health information acquired by people with low literacy skills?*
>
> *What approaches have been tried to provide health information to persons with limited reading skills?*
>
> *What other strategies might be considered?*

The response was overwhelming, both in terms of numbers (we received a total of 107 responses, representing response rates varying from 65 percent of public health units to 19 percent of community literacy groups) and in the richness of the information provided. For example, many respondents had personal experience of health problems related to illiteracy and were very appreciative of the opportunity of expressing their feelings on the subject. We were also provided with many specific examples of health problems as well as of approaches which have been tried to overcome them.

A content analysis was carried out on these responses whereby they were coded and grouped into common categories. Appendix A presents and summarizes these findings, indicating in particular the types of health problems identified, and tried and proposed solutions. A listing of the verbatim responses

and examples provided, grouped by categories, has also been prepared.[4]

The purpose of this method was to obtain a qualitative indication of the nature of literacy-related health problems, descriptions of examples of both these problems and of potential interventions, as well as an indication of interest and awareness. Thus the response rate itself is one indicator of interest in the topic. This method was not designed to quantitatively determine awareness levels or the incidence of health problems that were related to literacy.

d. Case Studies

Three case studies at different sites in Ontario were carried out. One was with a rural multi-service centre, one with a community health centre, and the third with a literacy program. The purpose of the case studies was to explore some of the issues identified through other methods in greater depth in a small number of settings. These involved a series of group and individual interviews with people associated with each site, including staff and consumers where possible.

e. Key Informant Interviews

We carried out a number of interviews with knowledgeable people throughout Canada and beyond, with individuals or researchers who were personally familiar with the area or who could refer us to other persons or to relevant documentation.

There was a high degree of consistency in the information obtained through our different methods. In other words, the observations reported via responses to the letters and via the case studies largely confirmed the statistics and research findings reported in the literature. They were also consistent with the observations of participants at the regional and provincial workshops which also formed part of the overall project. This consistency gives added confidence in the results obtained through the research.

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[4]Contact the OPHA (address shown in footnote 1, page 1) for information about the availability of this list.

3. WHAT IS LITERACY?

The concept of literacy is relative, rather than absolute. There are degrees of literacy ability, with no discrete cutoff point between "literacy" and "illiteracy". Literacy involves more than simple reading (or "decoding") of words, also including skill at comprehension and understanding and verbal reasoning ability (see especially Farrar, 1986). As the research of Eisemon (1988), Doak, Doak and Root (1985) and others has indicated, understanding is further influenced by one's familiarity with the context or "prior knowledge" of an area. Thus, for example, a communication about immunization may be incomprehensible for a person with no prior knowledge about microorganisms. This broader view of literacy has implications for the presentation and understanding of health information.

"Basic illiteracy" is a total inability to read or write. A more useful definition is "functional illiteracy" - a lack of sufficient reading, writing and numbers skills in order to get by in everyday life (e.g. Creative Research Group, 1987; Industrial Accident Prevention Association, 1982; Perrin, 1987; Rea, 1986; Woods Gordon, 1987). The concept is intentionally relative - the knowledge and skills an individual needs to cope are a function of the demands of a particular society or even of a particular community at a certain point in time. These demands can, and do change. For example, with an increasing move away from a manufacturing to an information-based economy, increasingly higher levels of reading, writing and numbers skills are being required, even for many entry-level jobs (Perrin, 1987; Rea, 1986).

The Southam Literacy in Canada study, completed in 1987 (Creative Research Group, 1987), is one of the very few to assess literacy ability through the use of reading assessment tasks. According to Southam, 24% of Canadian adults are functionally illiterate. If immigrants who speak neither of the two official languages are all excluded, the illiteracy rate of native-born Canadians is still 22%! Southam, in keeping with the relative nature of literacy, also identified an additional 9% who were classified as "moderately illiterate".

However, few direct measures of literacy are available. (Wagner, (1988) discusses potential approaches to the direct measurement of literacy.) Functional illiteracy is most commonly defined according to the Unesco guideline as less than grade 9 education. According to the grade 9 criterion, 21% of Canadians are functionally illiterate (Canadian Association for Adult Education, 1985).

The Southam study identified "false illiterates" (persons who were functionally literate but with less than grade 9 education) as well as "false literates" (persons who were not functionally literate even though they had more than grade 9 education). However, while grade level may not reflect the literacy level for a given individual, it only slightly underestimates (by about 5%) the literacy rate for a community or society. Thus, in spite of its shortcomings, it still is useful as a proxy indicator of literacy. Literacy has been assessed using the grade level method in almost all of the research studies reported in the literature.

Our study focused on illiteracy rather than on the inability to speak or read English or French. However, we also found that people, such as recent immigrants, who were literate only in their mother tongue, had similar health problems. In addition, written and oral communications which failed to take into account the cultural, or sub-cultural background of the intended audience, also contributed to a failure in understanding (e.g. Baker, 1987; Farkas and Spindell, 1986; IAPA, 1982; Kappel, 1988; Echenberg, 1987a; as well as our own data).

4. LITERACY AND HEALTH STATUS

The evidence is clear and unambiguous: illiteracy has a major, negative impact on health. This is the major finding of our research.

The initial focus of our study was on identifying specific health hazards resulting from a limited ability to read which could make illiteracy dangerous. Our findings, however, demonstrate, unequivocally, that virtually all aspects of the health of people with limited literacy skills are worse than for others.

There is no consensus about the best means of determining health. Different indicators of health status abound. However, no matter how health is measured, it is negatively affected by illiteracy.

Evidence for these conclusions comes from many different types and sources of information, from Canadian data as well as from elsewhere. Evidence from all the major Canadian health status surveys, as well as numerous research studies published in the health literature which are based upon many other data sources, all point to the same pattern. In addition to this hard data, the observations of health and literacy workers, reported in the response to our questionnaire, also support these conclusions. Indeed, as Leigh (1983) has indicated:

> *One variable has been strongly significant in virtually every study, namely, years of schooling completed. This finding emerges whether health levels are measured by mortality rates, morbidity rates or self-evaluations of health status and whether the units observed are individuals or groups.*

One of the most commonly used indicators of health is self reported health status (e.g. the question used on Canada's Health Promotion Survey (Health and Welfare, 1988) was: "In general, compared to other persons your age would you say your health is excellent, very good, good, fair, or poor?"). The Health Promotion Survey found that 27% of those with elementary school or less education rated their health as fair or poor; for those with some high school, this drops to 17%; high school graduation - 9%, some post-secondary - 8%, community college completed - 6%, university degree - 6%. Very similar findings of self-rated health were found on other surveys cited in footnote 2.

Another behaviourial measure of health obtained through the same health status surveys (also see Leigh, 1985) is activity limitation (e.g. Health Promotion Survey: "Are you limited in the kind or amount of activity you can do because of a long term physical condition or health problem?") Twenty-six percent of persons with elementary school or less reported an activity limitation, compared to 16% for those with some high school and 11% with a university degree.

People with limited education also have a higher rate of accidents, not only at the workplace but also at home and in the community (Advisory Council on Occupational Health and Occupational Safety, 1985; Canadian Occupational Health and Safety News, 1988; IAPA, 1982; Kenter, 1987; Leigh, 1983; Patterson, 1987; Ramirez, 1983). Infant mortality and development of the children of persons with limited literacy is also adversely affected (Grossman and Joyce, 1987; Kleinman and Madans, 1985; Sharav, Collins, and Shlomo, 1985).

As the title of Jenkins' (1978) editorial, "Low Education: A Risk Factor for Death", in the *New England Journal of Medicine implies*, people with limited literacy skills also have higher rates of morbidity and of mortality, and higher incidences of most forms of diseases. Grossman and Joyce (1987) found in their research that: "Schooling has a positive and statistically significant effect on the probability of survival." Pincus, Callahan, and Burkhauser (1987), in a review of the literature, have indicated:

> *Of the 23 health conditions reported by more than 1% of the population, 19 differed significantly in reported frequencies according to formal educational level. The relative frequencies of any reported condition in individuals with 1-8, 9-11, 12 years, and more than 12 years of formal education, were 3.6, 2.3, 1.4 and 1.0 respectively. Significant trends according to formal educational level were seen for all types of chronic diseases, including cardiovascular, gastrointestinal, musculoskeletal, neoplastic, psychiatric, pulmonary and renal diseases. These trends remained significant for all categories except neoplastic disease when formal education was controlled for age, sex, race and smoking.*

Numerous other studies have confirmed Pincus et al.'s findings and have documented the higher prevalence of diseases among people with low levels of literacy, as well as more serious consequences. Slater and Carlton (1985) discuss the evidence indicating the reliability of education as an indicator of mortality. For example, (Weinblatt, Riberman, Goldberg, Freank, Shapiro, and Chaudhary, 1978) found that

"men with little education (eight years or less) who had irregular heartbeats were over three times as likely to die as a result of sudden coronary death than those with better education and the same arrhythmia." Leigh (1988), Millar and Wigle (1986), Ruberman, Weinblatt, Goldberg, and Chaudhary (1986) have also reported on the relationship between limited education and cardiovascular disease.

Researchers such as Esdaile and Wilkins (1987) and Pincus and Callahan (1985, 1986) have explored the relationship between low education and rheumatoid arthritis. Examples of other diseases which Pincus et al. (1987) indicate have also been shown to be related to low education include diabetes and cancer.

In addition, people with limited literacy skills also suffer from greater hypertension, elevated cholesterol levels, obesity (as opposed to overweight), mental health and psychological distress (Statistics Canada, 1981, Pincus et al., 1987). These and other related factors (see the discussion on Healthy Lifestyle Practices in Section 5.b.i regarding indicators of wellness and health risk factors) are not only health problems in their own right, but are a factor in additional and more severe illnesses.

It is noteworthy that while the health status of persons with "some high school" is better than those with less education, it is significantly worse than those with high school graduation or more (e.g. see the example cited above from the Health Promotion Survey (Health and Welfare, 1988) regarding self-reported health status and the quote from Pincus et al. (1987) regarding incidence of diseases). Additional education beyond high school graduation only makes a minor contribution to improved health status. These data suggest, as does Southam (Creative Research Group, 1987), that the grade nine criterion of functional literacy may be an overly conservative indicator for the purposes of health status.

Many other factors in addition to illiteracy/limited education are also associated with poor health, such as age, income, and environmental factors. To what extent, if at all, might the health effects associated with literacy/ limited education actually be a result of one or more of these other factors? To what extent is illiteracy a cause of poor health status, rather than merely a covariate?

A variety of epidemiological and multi-variate studies have explored these inter-relationships in a variety of ways.

For example, Statistics Canada (1987) carried out a re-analysis of a variety of different measures of health status from the General Social Survey by education, but standardizing for age, and found that those with limited

education were still worse off, for virtually every measure of health examined. For example, even when age-adjusted, at least one and a half times as many people with, at most, some secondary education reported their own health status as fair or poor compared to people with more education. Similar unpublished reanalyses of age-adjusted data from the Quebec Health Survey also show that the impact of education on measures such as activity limitation persists. An unpublished reanalysis of data from the Health Promotion Survey found that while, initially, there was a strong relation between income and self-reported health, the income differences disappeared totally when this was controlled for education.

Grossman and Joyce (1987) point out that while health to some extent can influence schooling (the findings of the Ontario Child Health Study (e.g. Ontario Ministry of Community and Social Services, 1986, 1987; Offord and Boyle, 1986; Boyle et al., 1987) also support this position), causality is much stronger in the reverse direction. Labonte (1987a) cites data from Great Britain which challenge the "simplistic selection thesis" that poor health leads to lower socioeconomic status.

A variety of studies in the literature have explored the relative contribution to health of a wide range of other possible variables, and have all shown that literacy/ education is the major variable affecting health. Slater and Carlton (1985) cite U.S. data which indicates that the relationship between education and mortality is independent of income. Leigh (1985) examined some 20 other factors and concluded that: "Years of schooling persists as a predictor of good health regardless of which other variables enter the equation or in what manner health is measured." Grossman and Joyce (1987), based upon their own research and other research they reviewed, reached an identical conclusion.

Particularly dramatic is a report of the World Bank (Cochrane, O'Hara and Leslie, 1980) on the effects of education on health. This report discusses the findings of a number of different studies which explored the determinants of international differences in life span and mortality, using a variety of multi-variate statistical analyses. The report indicates that literacy is the most important variable associated with mortality, even more so than income and food intake!

5. NATURE OF THE IMPACT: THE INTERVENING VARIABLES

How does illiteracy lead to poorer health? The evidence suggests that this takes place through a combination of both direct and especially indirect intervening variables.

a. Direct Impact of Illiteracy on Health

The literature provided very limited information about the direct effects of illiteracy on health. However, the responses of community health and literacy workers to our questionnaire, as well as the case studies we conducted, identified numerous examples of health problems, often severe enough to require hospitalization, directly due to illiteracy. For example, numerous examples (all quotes are from responses to the questionnaire, unless indicated otherwise) of the following types of problems were reported:

* Incorrect use of medications,
* Not following medical directions,
* Errors in administration of infant formula,
* Safety risks.

i. Incorrect Use of Medications

Nearly half the respondents to our questionnaire provided illustrations of incorrect use of medications, or a lack of understanding of instructions about how to use medications. This involved both prescription drugs as well as over-the-counter medications. Medication errors, as a result of an inability to read instructions, have resulted in overdoses and in mixing up different medicines. Some of these errors were serious, e.g.:

> *Inappropriate administration of medication - both OTC and prescription. Clients go by colours and are confused if brand changes and pills change colour. Can't read directions, so underdose or overdose with adverse effects.*

> *Geriatric patient admitted to hospital with overdose of sleeping medication - couldn't read English or mother tongue and couldn't differentiate medications or remember when to take them - an accidental overdose.*

Client with epilepsy couldn't distinguish medication - thought they were all vitamins and couldn't understand why she was taking them.

Confusion between quantity of drug to take and times to take it.

Client hospitalized with severe anemia due to inability to read medication labels with dosages and take required iron medication.

Senior had colour and shape of pill changed - relying on these visual aids he continued to take his original prescription as well as a new one - thereby taking double doses.

ii. Not Following Medical Directions

We were given a number of examples of persons who would not comply with medical direction, due to an inability to read written instructions or because verbal instructions were not presented in a way in which they could be understood. Examples we were given included:

Diabetics who were not following prescribed treatment, who were not taking insulin, or who could not read food labels in order to avoid foods containing sugar.

Surgical procedures and test results may be poor or faulty because of incorrect patient preparation - instruction sheet too difficult to follow and not comprehended or complied with.

Forty-eight year old man had coronary - couldn't read instruction sheets re special medical procedures given by doctor.

Family discontinued use of contraceptive practices - no understanding of concept and couldn't read instructions/literature.

Mothers unable to read ingredients on labels to avoid substances that may cause allergic reaction in family members.

Two letters from doctors (Frankel, 1987; Rossof, 1988) recently appeared in *Lancet*, indicating their "eureka" experiences when they realized that what they had initially "mistaken for non-compliance was instead a simple inability to comply" due to an inability to read their directions and medication instructions.

iii. Errors in Administration of Infant Formula

Thirteen percent of the respondents to the questionnaire spontaneously identified misuse of infant formula, for example:

> *Unable to read directions on baby formula.*
>
> *Mothers not diluting concentrated formula and others diluting ready-to-feed formulas - babies at risk.*
>
> *Illiterate couple with bottlefed baby. Baby was "fussy" so father changed formula and gave baby almost undiluted carnation milk and then changed to whole milk - changed formula four times. Baby became very dehydrated and had to be hospitalized.*
>
> *Young student in literacy group was about to give newborn baby Enflack straight out of the can because she couldn't read instructions to mix it with water.*
>
> *New mothers who can't read or count well enough to prepare formula properly.*
>
> *Baby failing to thrive - mother couldn't read "good nutrition" literature left for her nor formula labels.*

iv. Safety Risks

These include the inability to read and comprehend safety warnings, particularly at the workplace. While no quantitative evidence about the incidence of accidents in which illiteracy has been a direct cause is available, some examples serve to illustrate problems which have arisen. For example, the Advisory Council on Occupational Health and Occupational Safety (1985) cites the following examples:

> *A worker who was unable to read was newly recruited to a construction site and was asked to obtain boots for the worksite. The boots purchased outwardly resembled those worn by other workers but, having no steel plate insert, subsequently played a part in an injury to the worker's foot.*
>
> *A worker was injured when handling chemicals that had safety instructions on the label, which he was unable to read.*

A pictorial instruction material demonstrating 'how not to' carry out a task was interpreted as a 'how to' instruction and the result was an increase in accidents.

Other examples of workplace safety risks given to us include:

Cannot read safety and health regulations, instructions in work area, on machinery, etc. Required to put complaints in writing but can't.

Students working in factories with hazardous chemicals have to rely on memory to keep different chemicals straight and not confuse them.

But not all safety risks are in the workplace. For example:

One learner had her child taken away from her because her baby became ill after playing in polluted water. The Children's Aid accused the mother of neglecting to read the warning signs posted in the area. The mother was too ashamed to say that she couldn't read.

Warning sign for pregnant women in x-ray room in hospital - written in several languages but not readable by illiterates.

Injury due to mistaken product - use of poisonous substance instead of safe product as unable to read labels.

b. Indirect Impact of Illiteracy on Health

Health problems such as those indicated above, resulting directly from an inability to read, are significant and dramatic. However, a striking finding from our research is that these direct impacts represent just the tip of the iceberg.

It is apparent, both from the research literature as well as from our own data collection, that the major impact of illiteracy on health status occurs <u>indirectly</u>. For example, as Leigh (1983) has indicated: "Evidence from two national surveys indicates that the indirect dominate the direct effects. . . . In terms of statistical significance, smoking, exercising and choice of occupation appear to be very important intervening variables between schooling and health." In another study, based upon longitudinal data, Leigh (1985) found evidence that schooling enhances health through: "1) allowing access to safer jobs, 2) reducing the number of hours unemployed, 3) reducing the consumption of cigarettes, 4) altering preferences toward risk."

The major indirect means we have identified through which illiteracy leads to poor health include:

* Poor lifestyle practices,

* Poverty,

* Stress and low self esteem,

* Dangerous work environments,

* Lack of access to health information, and

* Lack of use or inappropriate use of medical and health services.

i. Healthy Lifestyle Practices

People with limited literacy skills are more likely than are others to take part in a wide range of unhealthy lifestyle behaviours, and less likely to engage in preventative measures.

For example, people with limited literacy, in comparison with others:

* Smoke more;

* Have poor nutrition;

* Are less likely to engage in regular physical activity;

* Use seatbelts more infrequently;

* Among women, are less likely to practice breast self examination and to obtain pap smears;

* Are less likely to ever have had a blood pressure check;

* Are heavy coffee drinkers;

* Are less likely to have a fire extinguisher, smoke detector, or a first aid kit at home.

The above findings have been found, consistently, across a wide variety of surveys and research studies. In particular, they emerge from the major Canadian health status surveys cited earlier (see footnote 2). Indeed, about the only major risk factor where people with limited literacy were not worse off, according to these surveys, was with respect to drinking: people with higher levels of education drink more

in total, are more likely to drink to excess and to drive after drinking.

These findings also have been confirmed by respondents to our own survey. In addition to risky lifestyle behaviours over a number of dimensions, people with limited literacy are also less likely to be aware of the importance of healthy practices.

The impact of these risk factors on health is well documented (e.g. see Slater and Carlton, 1985). Indeed, the literature suggests that unhealthy lifestyle practices (e.g. Leigh, 1983, 1985; Grossman and Joyce, 1987) including the failure to practice preventative medicine, may be one of the major intervening variables accounting for the poor health status of people with low literacy.

However, findings from our own data collection, as well as statements in the literature (e.g. Echenberg, 1987a, b; Harding, 1987; Labonte, 1987a) caution against "blaming the victim": for many reasons, people with low literacy have limited opportunity to make informed choices about their own lifestyles. Illiteracy directly limits one's options and ability to make lifestyle choices. It also leads to the factors discussed in the following sections, which in turn restrict even further one's ability to follow healthy lifestyle practices.

ii. Literacy and Poverty

The impact of poverty on ill health has received considerable research attention and is well documented.

For example, the Black Commission in the United Kingdom (Townsend and Davidson, 1982), which documented health inequalities among the lower classes and the poor, has received considerable international attention. There has been considerable documentation in Canada as well of health inequities among the poor (e.g. all the major health status surveys previously cited; D'Arcy, 1988; Ontario Ministry of Community and Social Services, 1988; Rootman, 1988; Slater and Carlton, 1985; Wilkins, 1988). In particular, a background study for the Ontario Social Assistance Review Committee (Harding, 1987) has documented the relationship between poverty and health status, presenting evidence that poor people: experience higher rates of premature death, die younger, have more illness and are ill more often, have fewer years of life that are disability free, and are less happy.

The National Anti-Poverty Organization, in a review of community-based literature (Echenberg, 1987a, b), found "an inexorable link between low income and higher mortality and

morbidity" and a surprising consensus that health inequities created by poverty result from hunger/malnutrition, unhealthy environments, and from stress. Labonte (1987a) has eloquently explored some of the mechanisms whereby lower socio-economic status leads to poor health.

To what extent are health problems attributable to illiteracy rather than to low income and poverty? While, of course, lack of education and literacy skills are not the only reason for poverty, they clearly are the major factor, a basic prerequisite in most cases to enable persons to obtain employment and consequently sufficient income in order to avoid or to escape poverty.

For example, over half of social assistance recipients in Ontario are functionally illiterate. Only 40 percent of Ontarians with less than grade nine are employed; 55 percent are not even in the labour force. And those functionally illiterate people who are employed are more likely to be working in low paying, low skilled, marginal jobs, with poor job tenure. These and other factors have led the Social Assistance Review Committee (SARC, 1988) to conclude that: "Members of the committee take it as a given that a basic level of literacy and numeracy is a prerequisite for almost any job."

In addition to illiteracy being a major cause of poverty, it is also a basic prerequisite in order to enable people to escape from poverty. Our society and the job market is changing such that, as Rea (1986) has indicated: "Quite simply, it will be considerably more difficult for an illiterate or semi-literate to find gainful employment in an increasingly information-based economy."

Not only are literacy skills required to obtain almost any job which would pay enough to permit a person to live above the poverty line; many training programs have educational prerequisites of grade 10, 11 or 12. Thus functionally illiterate persons cannot even qualify for admission to training programs, including programs such as the Employment Support Initiatives Program of the Ministry of Community and Social Services which are specifically designed to assist social assistance recipients in acquiring skills to achieve independence.

Furthermore, a number of statistical analyses which have controlled separately for the effects of education and of income indicate that, while both are associated with ill health, lack of education is the predominant factor. For example, an analysis of the Health Promotion Survey found that when controlled for education, the initial relationship between income and self-reported health drops out. In other words, apparent effects of income on self-reported health in

this survey are actually a result of education/literacy. Similarly, a reanalysis of Statistics Canada's 1976 Survey of Fitness, Physical Recreation and Sport found that education accounted for a much larger share than did income or any other factors of the differences in physical activity rates.

There have been few Canadian attempts to examine more comprehensively the relative contributions of the various components of socio-economic status (i.e. literacy/education, income, occupation) on health status. However, this has been done in other jurisdictions. For example, Slater and Carlton (1985) have indicated that "the education differentials probably provide more reliable indicators of socioeconomic differentials in mortality in the United States than do income differentials. Grossman (1987), following a review of a variety of studies, concluded that "schooling is a causal determinant of the two other components of socioeconomic status - income and occupation" and cites 10 separate studies in the United States that all indicate that "schooling is a more important correlate of health than occupation or income". In a study of correlates of cancer knowledge, Stone and Siegel (1986) found that while income initially appeared through bivariate analyses to be associated with cancer knowledge, a multivariate analysis found that this was a spurious correlation, accounted for by the association with education.

The purpose of this discussion is not intended in any way to minimize the direct influences of poverty itself on ill health. On the contrary, poverty, as discussed previously, directly affects health in many ways. It is clear that the effects of illiteracy, poverty and health are related and interdependent in many ways. But given that low income and poverty to a large extent result from illiteracy, so do the health problems associated with it.

iii. Stress and Low Self Esteem

Both the literature and observations reported to us via our survey and case studies highlight the connection between illiteracy, stress, and ill health.

People with limited reading skills tend to be under a high level of stress and to have limited self confidence. For someone who cannot read to attempt to function in a world where the ability to read is taken for granted, and a requirement for many basic day-to-day activities, is extremely trying and stressful in its own right. One must "make do" without information available to those with better reading, writing and numbers skills. In turn, this leads to frustration, anger, and even feelings of shame. People with low self esteem also find it more difficult to seek and find

employment or to socialize with others, which in turn leads to even greater stress and increased risk of health problems.

Inability to read well enough to meet society's literacy demands results in a feeling of vulnerability and a sense of lack of control over one's life. Indeed, this vulnerability is very real. For example, most persons with limited literacy skills are unemployed and those jobs which are open to them, as we have already discussed, generally are of low status, of limited tenure, and provide employees with little say over working conditions. Others who are on social assistance are perceived by society - and by themselves - as having given up their independence and social standing. The resulting poverty from illiteracy, as discussed in the preceding section, brings on an additional range of stressors to the extent that the National Anti-Poverty Organization (Echenberg, 1987a, b) identified stress as the major health hazard affecting people living in poverty.

Many people who cannot read live in constant fear of being "found out" and the consequences this can bring - ranging from ridicule, even less self esteem, as well as material consequences such as loss of employment. One learner, for example, indicated how she, and most other people who cannot read, hide this, but at the cost of "the stress of presenting an image so you don't feel stupid." Attempting to disguise illiteracy is extremely trying.

Many people lacking in literacy skills are extremely resourceful in functioning in spite of this limitation. Nevertheless, literacy itself is a basic skill, and there is clear evidence that people lacking this skill may have limited resistance in coping with environmental stresses when these do occur. For example, in our research we heard of a situation where a mother, new in town, did not know where the hospital was nor how to use the phone book to find out when her child was injured.

A number of researchers have concluded that difficulty in coping with stress is a major mechanism linking illiteracy to ill health. For example, Wilkins (1988b), in his analysis of Canada's Health Promotion Survey, found that "the well-to-do appear to experience fewer stressful events and to be less disturbed by such events when they occur." Jenkins (1978) indicated:

> *The poorly educated may often be limited in interpreting circumstances and resolving potential problems before they grow to distressing proportions. Persons at lower social strata encounter more negative life changes and may also encounter more interpersonal conflicts. . . . Thus, inadequate edu-*

cation not only may place a person at greater risk of painful experiences, but also may represent a deficiency in resistance to environmental stressors.

Stress is a major health problem in its own right. For example, stress is a major factor in depression, anxiety, and other mental health problems. We have heard of at least one case where the stress of being found out, when a company was about to computerize its operations, led to suicide.

But stress also leads directly to the subsequent occurrence of illness and diseases of all sorts. For example, the researchers who documented the higher rate of death among people with complex ventricular premature heart beats who had limited education (Weinblatt et al., 1978) hypothesized that this may be a result of more common or more persistent or more profound social and psychological stresses facing people with limited education.

Other research, in particular the well known Alameda County study (Beckman, 1984) has shown that people who lack social and community ties have a shorter life span than those with more extensive contacts. The Ontario Child Health Study (Offord and Boyle, 1986) found that the health of persons on social assistance was considerably worse than for others, even with equivalent incomes. This was attributed to the sense of apathy and powerlessness which frequently is associated with receipt of social assistance. Labonte (1987a) in particular has articulated mechanisms linking factors such as self esteem, social support, and stress to health.

In addition, limited self confidence often results in persons being less likely to seek medical help and in asserting themselves, which in turn can result in health problems. For example, we were told of a number of situations where people who could not read would refuse to go to health professionals (e.g. for an eye examination!), for fear of being "found out" or of having to give up control, until their health problem has turned into a crisis.

But we have also heard of how literacy can assist persons in being more assertive. For example, one client of a community literacy program gained self confidence along with her increasing reading ability. After waiting two to three hours each time she went to the doctor, she started to question why she was still waiting while others who came later had already seen the doctor. Now she also has the self confidence to ask about her medications, what they are for and how they are supposed to help.

iv. Dangerous Work Environments

Workers with limited literacy skills appear to have a higher than average rate of occupational injuries. This seems to be mainly because the types of jobs open to them are more likely to be hazardous (Accident Prevention, 1985; Advisory Council on Occupational Health and Occupational Safety, 1985; Industrial Accident Prevention Association, 1982; Leigh, 1983; Ramirez, 1983). For example, a disproportionate number of persons who are functionally illiterate are employed in primary, resource and construction industries. Accident rates in these industries are well above the average across all workplace settings.

In addition, much information about occupational health and safety is available only in written form, and consequently workers who cannot read are less likely than others to be aware of the existence of dangers at the workplace. This was confirmed by our own data as well as in the literature (e.g. Canadian Occupational Health and Safety News, 1988; Grueninger, 1986; Kenter, 1987; Patterson, 1987; Samways, 1988; Towler, 1988; One study of literacy students (Advisory Council on Occupational Health and Occupational Safety, 1985) found that:

* Almost all participants had the need to read material related to occupational health and safety and that all had experienced some difficulty in doing so;

* Most ignored instructions they could not read;

* Only about one-half had been provided with oral explanations of jobs.

Furthermore, people with limited literacy skills are less likely to be aware of the existence of dangers at the workplace and of their rights under occupational health and safety legislation. And even if they are, due to their limited advocacy skills and the lack of "job purchasing power", these workers are unlikely to be in a position to assert their rights.

For example, the Advisory Council (1985) pointed out:

> *Practical difficulties in finding and obtaining employment, fear of losing one's job if lack of literacy is discovered, limited job options and lack of confidence can be expected to inhibit the illiterate worker from speaking out and from effectively participating in the resolution of health and safety problems in the workplace. Those who are functionally illiterate tend to be operating from a position of social and economic disadvantage, and the 'stigma' associated with illiteracy*

may cause the illiterate to hide an inability to read, write or comprehend written material or to fail to seek help.

The available evidence, as Ramirez (1983) suggests, is that it is the job and not the worker who is dangerous. As the Advisory Council (1985) indicated, the problem lay not with illiteracy and language fluency itself, "but rather with the presence of hazards in the workplace and/or insufficient or inappropriate instruction or training."

v. Access to Health Information

Much health information is inaccessible to people with limited literacy skills. This is a result not only of the inability to read written materials, but also because many people obtain their information about health from sources other than the written word. In addition, even much verbal information is not presented in a way in which it can be understood.

Inability to Read Written Information

Much, perhaps most, health information is in written form and hence inaccessible to people with limited literacy abilities (e.g. Breen and Catano, 1987). This includes both information about health produced by health and social services organizations, as well as printed information available through the popular press and other sources.

For people who read, it is hard to avoid coming into contact with a wide range of information about all aspects of health. It is hard to pick up a newspaper or a general interest magazine without finding, for example, reports of recent medical advances and guidelines for health care, news reports about health and safety risks, columns and articles with titles such as "Your Health" or "Your Nutrition" which provide suggestions for healthy living along many dimensions, as well as how to use health care. The popular press also provides information about safety on a regular basis. Thus this information is inaccessible for people who cannot read.

The written word, via hundreds if not thousands of pamphlets and brochures, is probably the major vehicle used by health agencies for transmitting information about health care and health lifestyles. There has been increasing recognition within the health community that much of the written material available is overly complex, unreadable even by many people whose reading ability may be well in excess of accepted definitions of functional illiteracy, and should be prepared using more simplified language (e.g. Breen and Catano, 1987; Cole, 1979; Doak et al., 1985; Farkas, Glenday, O'Connor, and Schmeltzer, 1987; LaPierre and Mallet, 1987). Thus most

material specifically designed to provide information about health is also inaccessible to people who cannot read.

Lack of Information in Alternative Formats

This developing interest in readability will expand the accessibility and usefulness of written materials to many people. However, many others will still be unable to read any written information, no matter how simplified the language.

And others who in theory could read will not. As a number of our informants indicated, the printed word in not a preferred or trusted means of acquiring information for many people. Many persons choose to obtain information, about health as well as about other topics, from other sources. For example, when respondents to our questionnaire were asked where people with low literacy skills acquired health information, the most common response was by word-of-mouth, in particular from family and friends. The Southam study (Creative Research Group, 1987) found that most people who could not read well had no desire to do so. Thus many people, with or without the ability to read, are unlikely to use pamphlets and other forms of written health information.

Information Not Presented Understandably

There are increasing attempts to provide translations of a number of brochures into other languages. However, we have been told that many of these translations are overly complex in the language to which they are translated and hence are not readily understandable. Much health information, in whatever form, may be culturally inappropriate (e.g. Farkas, 1986). Material may need to be adapted rather than translated for it to be meaningful and understandable.

Use of symbols has sometimes been suggested as a means of communication with people who have limited reading skills. However, many symbols are also incomprehensible; generally the more abstract a symbol is, the less likely it will be understood. Understanding of a symbol also is related to previous experience with the symbol and with the context in which it applies. Thus for these reasons, symbols are even less meaningful for people with limited literacy skills than for others (Doak et al., 1985, Eisemon, 1988, Patterson, 1987.

Some of the available information and advice about health often may appear contradictory to the layman. The greater the literacy and comprehension skills people have, the more likely that they will have been able to acquire a better general knowledge understanding of health issues. This general knowledge will assist them in making sense of new

information and identifying what they should do about it. Greater comprehension skills as well assist in the ability to understand at least some of the complexities raised even in the lay literature.

Verbal directions and explanations from medical and health practitioners are frequently not understood by persons with limited literacy abilities. Literacy, as we discussed in Chapter 3, is more than just simple decoding of written words; it also involves comprehension and understanding. We were provided with numerous examples in our research of persons who could not understand, and consequently were not able to follow, verbal directions given to them, and of practitioners who neglected to check if the persons they were speaking to understood what it was they were saying.

People with limited literacy skills tend to have a limited vocabulary and limited prior knowledge of health. They rarely come from the same middle-class background as most medical practitioners. For health messages, of any form, to be received and understood, basic principles of communication need to be followed; these involve adapting messages to fit within the context of the intended recipient and testing for actual acquisition and understanding of the information. Unless factors such as these are taken into account, verbal - as well written information - from health practitioners to people with limited literacy is impossible to understand.

In addition, written materials are used frequently by health practitioners as backup or reminders to verbal directions. For people who cannot read, this option of course is not open to them.

As a result - due to an inability to read written health information, lack of information presented in appropriate and trusted media, and even verbal information which is frequently not presented understandably - it is hardly surprising that many people with low literacy skills tend to have a limited understanding of health issues, and often considerable misinformation. This has been documented through the literature (e.g. Doak et al., 1985; Eisemon, 1988; Grueninger, 1986), as well as numerous reports through our questionnaires, cases studies, and interviews.

Health promotion efforts have been credited with recent improvements in health practices among the general population, for example in decreases in the numbers of smokers and in improved dietary practices. While the impact of health information on actual health behaviour and on health status has not been well evaluated, there is solid evidence (e.g. Slater and Carlton, 1985; Israel, 1986) which shows that health promotion can make a difference. To the extent that written health information has any value, then the inaccessibility of this information to persons with

limited literacy can only have a negative effect on their health.

vi. Lack of Use or Inappropriate Use of Medical and Health Services

We have reviewed considerable documentation given to us in the course of our research that many persons with limited literacy skills are unaware of where to go for needed health services. Many people do not know what community or health services are available and if they do, do not know how to access these services. They often do not have the skills to find out necessary information about health services.

This can be at a very basic level. For example, we heard of examples of persons who did not have OHIP (provincial government health insurance), either because they were not aware of OHIP at all, of the availability of premium assistance, or because they could not fill out the necessary forms to qualify. Another case reported to us was about a young boy who fell and cut his forehead near the eye: his mother was new in town, did not know where the hospital was located, and was unable to use the telephone book.

Others may be afraid to ask for help, due to embarrassment over their illiteracy, or may be intimidated from asking for assistance. As one health worker indicated, for example:

> *Clients' self-consciousness about not knowing how to read is a major problem. They are shy about asking the doctor or social worker to explain to them the instructions on prescriptions, the terms of their ailments. . . They prescribe over-the-counter medicines for themselves based on the recommendations of friends.*

Illiteracy also leads to inappropriate use of medical services. For example, people with limited literacy sometimes have difficulty keeping track of appointments or following directions. In at least one case reported to us, surgery had to be postponed on a patient because of inability to read the hospital's pre-admission directions. Some people over-react to perceived health problems, and others make unnecessary use of hospital emergency departments. But in many other cases, people with limited literacy skills, for a variety of reasons, neglect preventative care and wait to seek medical help until a health problem has reached a crisis state. As Leigh (1983) has indicated, education enables wise use of medical care.

In addition, as we have previously discussed, compliance with medical directions may be poor among people with limited literacy skills. This is partly because of the inability of people to read or understand written instruction sheets or

prescriptions. More often, however, it is a result of lack of understanding of verbal directions, due to the failure of medical workers to present information and direction so that it could be understood. As Frankel (1987) and Rossof (1988) pointed out, based upon their own experiences as doctors, medical staff may never be aware that "lack of compliance" may in fact be an inability to read and understand!

c. Summary

As this chapter has indicated, literacy affects health through a variety of direct and especially indirect intervening variables. A consideration of these factors suggest three underlying themes: lack of knowledge and skills, lack of resources, and lack of empowerment and control.

Lack of Knowledge and Skills

Persons with limited literacy ability tend to have only a basic knowledge of health concepts and what constitutes healthy and safe lifestyle and health practices. They have limited ability to improve their living conditions related to health, limited knowledge about how to go about obtaining information and assistance, and limited knowledge about how to use health services effectively. Lack of literacy skills limits their access to written, as well as to much verbal, information about any of the above.

Lack of Resources

Persons with limited literacy skills tend to be living in poverty. As a result, they are often unable to buy access to healthy and safe living conditions, food and medical supplies, health services, and other factors which contribute to healthy living.

Lack of Empowerment and Control

Illiteracy, as we have discussed, leads to a lack of control over many aspects of life. People who cannot read are under a great deal of stress, due to a multitude of factors. They have limited self-advocacy abilities and frequently feel (and indeed are) very vulnerable - in general, as well as to many specific situations and to environmental stressors. They have few options - for example, most are unemployed; others have little negotiating power in seeking a safe job. They have limited control over their access to health care services. In summary, they have little control over their own health.

6. AWARENESS OF THE PROBLEMS RESULTING FROM ILLITERACY

a. Awareness of the Issue

Many people within the public health and the literacy communities are aware of the potential impact of illiteracy on health. For example, the response from public health units to the questionnaire used in our study indicated that many public health workers are aware of the problem, have thought about it and are struggling to deal with it. Many public health workers were able to provide us with specific examples of literacy-related health problems, as well as with approaches they have taken to attempt to combat these (see Appendix A).

However, these same respondents indicated that they feel isolated and appreciated the opportunity to talk about their encounters with illiteracy. For many, this was the first opportunity they had to discuss the topic. Others felt that they were a voice in the wilderness, that others they worked with had no understanding of the problem.

But many others - over 20 percent of those who responded to the questionnaire, and probably many of the others who chose not to - indicated that they are not aware of the relationship, if any, between literacy and health. For example, a number of District Health Councils indicated to us that while they would be interested in hearing about the results of our study, this was not an issue to which they had given any thought or consideration. Still other respondents denied outright that illiteracy could result in any health problems! For example, one doctor we interviewed said that health problems were not a function of illiteracy, but rather of "lifestyle"; the connection between the two was not obvious to him.

And it appears that most people cannot comprehend the full extent of illiteracy in our society. For example, a survey by Westmount Research (1986) found that only 11 percent of Canadians were able to estimate correctly how many people are lacking in literacy skills. While there is no data about awareness among health workers, all indications are that they similarly fail to comprehend the magnitude of the literacy problem.

One of the top three suggestions among respondents to our questionnaire was to enhance awareness of health care professionals about the problems of illiteracy and how they should respond.

b. Awareness of What to Do

As we have discussed earlier, many people who cannot read go to considerable effort, for good reasons, to disguise their illiteracy, from health workers as well as from almost everyone else (e.g. Grueninger, 1986; Towler, 1987). Many of the respondents to our survey who <u>are</u> aware of the problem indicated the need for training and other assistance, in order to assist them in tactfully recognizing when illiteracy may be a factor, and how to respond appropriately. They said, for example, that health workers need assistance in how to identify illiteracy among their clients and in the development of skills in order to be able to provide information in appropriate formats for people who cannot read.

Some medical and health workers disclaim any responsibility on their part for taking the presence of illiteracy into account in their actions. For example, the questionnaire responses and the case studies identified the presence of viewpoints such as: "It's a job for the education sector, not for health workers"; "If people do not understand what I say, it's not my problem, I don't have time to explain everything in simple language"; and "It's the job of the health educator, not for me to worry about".

However, it is apparent that probably most professionals in the health area are simply <u>not</u> aware of the problem of illiteracy or that many persons disguise their inability to read or to understand. Nor have they considered that "lack of compliance" may be no more - and no less - than the inability to read or to understand complex verbal directions.

7. POTENTIAL SOLUTIONS

While the primary purpose of the research was to explore the relationship between illiteracy and health, the study also identified many potential means of addressing the health problems which were documented. Some of these ideas came from the literature, but many were provided by the respondents to the questionnaire and from the case studies. Numerous, often very specific, suggestions were provided. A full list of these is provided elsewhere (see footnote 4 on page 4). A number of the ideas suggested have been tried by health workers in various parts of Ontario.

Potential solutions which have been identified can be grouped as follows:

a. Social Policy Level Action

i. A Societal Commitment to the Reduction of Health Inequities

Health inequities such as those identified in this report, arising from illiteracy as well as from other socio-economic factors, can only be eliminated through concerted action by all sectors of society. While the health consequences of illiteracy may be medical in nature, resulting in increased mortality and morbidity, the solutions for the most part require non-medical interventions. For example, action is required in the development of healthy public policy, making workplaces safer, improving living environments, ensuring the delivery of education for all, and along other fronts. Health and Welfare Canada's (1986) health promotion framework, Achieving Health for All, speaks of the need for non-medical approaches to the reduction of health inequities, as do many others (e.g. Grossman and Joyce, 1987; Labonte, 1987a, 1988; Leigh, 1983; Rachlis and Kushner, 1989; Rootman, 1988; Slater and Carlton, 1985; Townsend and Davidson, 1982).

For this to happen, commitment to action is needed by politicians, all levels of government, business and labour, the media, and the public. The evidence suggests that any remedies which do not involve a major commitment and action across many different fronts would only be tinkering and would be unlikely to result in any major impact on existing inequities in health status. As Slater and Carlton (1985) have stated: "Whatever differences there are in these social conditions that promote ill health may have to be corrected primarily by massive social change."

ii. A Commitment by the Health and Medical Communities to the Reduction of Health Inequities

The existing health care system in many respects perpetuates rather than attempts to minimize the systemic barriers resulting in unequal health services and unequal health outcomes (e.g. Rachlis and Kushner, 1989).

Limitations in our current approach to health care have been well documented. So have needed changes. For example, three major reports which have examined the health care system in Ontario (Spasoff, 1987: *Health for All Ontario*; Podborski, 1987: *Health Promotion Matters in Ontario*; and Evans (1987): *Toward a Shared Direction for Health in Ontario*) have all recommended major changes in the manner in which health services are provided. Health and Welfare Canada's framework for health promotion: Achieving Health for All (1986) is also dedicated to the reduction of health inequities. The Ontario Public Health Association recently identified the reduction of health inequities as a priority.

None of these strategies specifically address the problems of illiteracy as such (although Rachlis and Kushner (1989) identify the redirection of funds from medical services to the reduction of illiteracy as one needed strategy). However, action to address literacy-related health problems is consistent with the direction in all these proposed frameworks. Action on the recommendations of these reports would address many of the indirect impacts of illiteracy identified by our research study.

The evidence suggests that the health and medical communities need to make a commitment to the reduction of health inequities. This requires action at the individual practitioner level, for example in the provision of appropriate and culturally sensitive health services for disadvantaged people, including people with limited literacy skills. However, individuals can only do so much. For significant change to occur, as the above-noted reports indicate, a different way of looking at health is required. This in turn has implications for restructuring the way health services are organized and provided and for changes in health priorities.

iii. Improved Living Conditions For People Living in Poverty

Many of the negative health consequences for people with limited literacy abilities, as documented in Section 5.b.ii, are as a result of their poverty. Improving their living conditions and level of income can assist in combating these health problems.

The *Achieving Health for All* framework of Health and Welfare (1986), for example, identifies healthy environments as one of its recommended mechanisms for health promotion. More specifically, the Social Assistance Review Committee (1988) thoroughly investigated problems of people living in Ontario on social assistance, as well as the working poor. As part of its investigation, the committee considered the effects of illiteracy as well as health problems of the poor, and made 274 recommendations for reform of the present system.

Implementation of these recommendations, for both short and long term action, can go a long way towards overcoming the health problems associated with poverty.

iv. Reduce Illiteracy by Teaching People to Read

Many respondents to our questionnaire, as well as researchers (e.g. Grossman and Joyce, 1987; Leigh, 1983; Rachlis and Kushner, 1989) in the area, have said that one of the best ways of addressing the health problems associated with illiteracy is by teaching people to read. Indeed, a number of medical economists have indicated, as have Slater and Carlton (1985), that: "Each additional dollar spent on education reduces mortality more than each additional dollar spent on medical care."

Towler (1988) suggests that business should respond to the illiteracy problem by:

> *Remedy[ing] the situation by offering remedial reading courses to those who need it; . . . insist-[ing] that governments pay more attention and do more to prevent the spread of illiteracy; demand-[ing] they develop adequate remedial programs, spend more money per illiterate and ensure the problem doesn't occur in the first place.*

Reduction of illiteracy requires a variety of strategies (Perrin, 1987), such as:

* Preschool programs for children from socially disadvantaged environments;
* Improved education at the primary and secondary levels;
* Greater attempts by the education and social service systems to reduce high school dropouts;
* More opportunities for literacy training for adults.

v. Commitment to Greater Safety at the Workplace

As discussed earlier, a major factor affecting the health of persons with limited literacy is that those jobs which are open to them tend to be dangerous. More accessible safety information, i.e. in other than a written form (e.g. Grueninger, 1986), as well as adequate training (IAPA, 1982) can help to some degree. It is also important that the responsibility of the employer include testing for the actual receipt and understanding of safety knowledge, rather than the mere provision of materials. But for any substantive changes in the reduction of workplace injuries, there is need for a greater commitment to making the workplace safer (e.g. Leigh, 1983; Ramirez, 1983; Rea, 1986).

b. Heightened Awareness within the Health Community

Awareness of the extent and nature of the problems associated with illiteracy is a prerequisite for action by the health community. Many of the respondents to our questionnaire pointed to the need for increased awareness and education among health medical and social service workers:

* To increase awareness about the incidence of illiteracy and how it affects the health of a substantial proportion of the population; and

* In assisting health workers, through training and other means, in recognizing when illiteracy may be a factor and how to deal with the problem, tactfully and effectively, while maintaining the dignity of the person.

A number of specific suggestions about how to accomplish the above were provided. For example, these included: awarenessraising workshops and consultations, skill-training sessions to show health workers how to communicate clearly, and liaison between health professionals and literacy workers. Another suggestion was, that with virtually 25 percent of the population functionally illiterate, health workers such as pharmacists should assume, unless they have reason to believe otherwise, that their clients cannot understand written instructions and explain these verbally as a matter of course.

c. Work Together with the Community

One of the effects of illiteracy is a lack of empowerment and control over one's life. As previously discussed, this feeling of helplessness produces a high degree of stress, and in turn health problems.

Therefore, one potential approach to combating health problems associated with illiteracy is to work in partnership with persons with limited literacy skills, assisting them to help themselves and to take control over their own health (Rootman, 1988). This is consistent with the health promotion mechanisms of self care and mutual aid proposed by Health and Welfare (1986). Labonte (1987b) indicates that use of a community health promotion planning model enables the community, rather than outside "experts", to define its own problems and concerns. Hubley (1984) indicates that it will be difficult to bring about any change in health practice if it does not meet a felt need of the community, is not seen by the people to convey real short term benefits, and cannot be modified to fit in with the local community.

A variety of community development and popular education approaches can permit active and meaningful involvement of consumers. While they can also work well with people who can read, they have been used extensively in developing countries with low levels of literacy. These approaches can also include working together with existing social networks in the community, including a wide range of community organizations such as community literacy groups, women's groups, antipoverty organizations and others, and can involve a wide range of techniques including photoessays, sociodrama, role play, pantomime and song, and many other means.

It is also helpful to recognize that people who do not read nevertheless have other channels of acquiring information, and that effective health education strategies acknowledge and use existing social networks. For example, Vanderberg, Prouty, Mwakikoti and Beeftu (1987) have discussed how children can be a vehicle for transmitting health information to family members as well as to the children themselves.

As we indicated in Section 5.b.v, our research found that the major means people with limited literacy use in acquiring health information is via word of mouth. To be sure, this often results in considerable misinformation. Nevertheless, it serves as a communications channel which is perhaps the most valuable way to influence actions. Hubley (1984) - as well as our own research - indicates that communities frequently have individuals who have considerable influence in their community; an effective health education approach might be to seek out these leaders, try to obtain their support, and providing basic training where appropriate. As Hubley adds: "Local taboos are rarely obstacles to implementing health education; indeed, many traditional beliefs are sound and may actually support the health education programme." Israel (1986) points out that a major factor in the success of many of the larger-scale health education programs appears to be the ability to organize and make use of support networks.

MacDonald and Zandstra (1988), in a review of international trends in health education, have indicated that: "Health education is moving from purely information dissemination towards an active role in helping people and communities to understand and change their own social environments and thus to promote their own health." It is apparent that we in Canada can learn from approaches to health education used in developing countries.

d. Provision of Health Information Other Than Via the Written Word

It is apparent that for people who cannot understand the written word, it is necessary to use non-written forms of providing health information. This comes from our own research, from the literature - and is basic common sense. For example, Israel (1986), in the introduction to an international review of actual health education projects, points out that the major lessons learned from these interventions include:

* The need to send messages through multiple channels of communication (mass media and interpersonal) in order to maximize impact;

* The importance of support networks.

Hubley (1984) describes the following characteristics of effective health education:

* Directed at people who have influence in the community;

* Repeated and reinforced over time using different methods;

* Adaptable, and uses existing channels of communication;

* Entertaining and attracts the community's attention;

* Uses clear simple language with local expressions and emphasizes short term benefits of action;

* Provides opportunities for dialogue and discussion to allow learner participation and feedback on understanding and implementation;

* Uses demonstrations to show the benefits of adopting practices.

Our own research (see Appendix A) indicates that many different non-written approaches to the provision of health information are already being used by public health workers

in Ontario, and a number of other suggestions were also provided. The most common approaches include the following:

* Use of pictures, symbols, and audiovisual aids in communicating health information and medical directions;

* Use of one-on-one interventions and demonstrations, as well as small group sessions;

* Use of creative strategies (e.g. drawing picture of a clock showing when to take medication; use of a volunteer to assist a client with a coronary who could not read in following medical directions);

* Television and radio.

The mass media has been used effectively, on occasion, as a health education approach (e.g. Slater and Carlton, 1985; Puska, Wiio, McAlister, Kiskela, Smolander, Pekkola, Maccoby, 1985). However, these approaches, as suggested by Israel (1986), also employed a variety of other complementary strategies.

Furthermore, there are major limitations to the use of media for health education which severely restrict its effectiveness. For example, both a number of respondents to our questionnaire, as well as the literature (Stone and Siegel, 1986), indicated that persons with limited literacy skills, to a greater extent than others, watch mainly entertainment rather than informational programs. As Israel (1986) says:

> *We are tempted by the flashiness of television and radio to expect great things from an investment in a mass media blitz; but over and over again, we learn the lesson that media, by itself, especially in short-term situations, can do little more than raise awareness.*

Labonte (1987b) says that health education, on the other hand, should increase a person's ability to analyze and understand a health issue.

e. Simplifying Written Information about Health

We have deliberately placed this topic last. To many people, producing "readable" health information is "the answer" to the problem of illiteracy. However, our research suggests that this viewpoint is shortsighted. Despite the fact that numerous respondents to our questionnaire suggested improving the readability of written information as one means of providing health information to persons with limited literacy

skills, it is apparent that written health information, however simplified, can be of only limited usefulness.

Many respondents indicated the need to simplify the language used in brochures and other written health information. Related suggestions included: testing for readability, pretesting for comprehension, use of large print, "friendly" formats with increased use of pictures and white space, more translations into other languages, etc. There has already been increased awareness within the health field of the need to simplify the language of written information (for example, the Ontario Public Health Association seminar: "Life Beyond Pamphlets" was a sellout), and increased efforts at producing "readable" health information.

To be sure, increasing the readability of those written materials which <u>are</u> used is undoubtedly worth doing. For many people with some reading ability, this will make accessible a wider range of information about health. As we indicated earlier, however, many people will still be unable to read, no matter how simplified the language; others who in theory <u>could</u> read will not, as they prefer obtaining their information through other means.

Furthermore, as the discussion on the preceding pages pointed out, there are far more effective means of health education than distribution of pamphlets and other forms of written materials. The more fundamental question is not if health education brochures are readable, but if and when they should be used as all. Thus enhancing the readability of written materials should not be viewed as a panacea to the problems of illiteracy - or of health education.

8. PRIORITIES FOR RESEARCH AND EVALUATION

A wide range of research studies has clearly documented the association between illiteracy and poor health. However, most of the evidence is correlational in nature. In most cases, assessment of literacy has used the proxy measure of education rather than direct measurement. There is a need for research to explore directly some of the intervening variables linking illiteracy to ill health. For example, there is a need for more multi-variate analyses of existing health status data, in order to separate out the effects due to literacy and education from other factors.

Medical research is almost exclusively devoted to exploring the biomolecular causes of illness. However, as Grossman and Joyce (1987), Rachlis and Kushner (1989) and others have indicated, social causes, such as illiteracy, are bigger determinants of ill health. Research priorities should be reversed to reflect this reality.

Nevertheless, while additional research could tell us more about the specific mechanisms by which health problems may result from illiteracy, it is already quite clear that illiteracy <u>does</u> result in significant health problems.

Thus a higher priority for additional research would be to focus on the best means of <u>avoiding</u> and minimizing these problems. There is a need for <u>action</u> research, involving the community, including persons with limited literacy skills. Research is needed which would obtain information from people with limited literacy skills <u>directly</u> - about their experiences and what types of approaches they feel would help them.

There is also a need for program evaluation. Longitudinal studies documenting <u>changes</u> in health status following the acquisition of literacy skills, preferably using controlled research designs, where appropriate, would assist in substantiating the nature of the problem and the need for action.

A number of potential - but largely untested - solutions, such as those listed in the preceding section, have been identified. But which of these strategies would be most effective? Under what circumstances? For whom? Research and evaluation addressing questions such as these can assist health and literacy workers in working to combat the health problems associated with illiteracy which this study has identified.

9. CONCLUSION

This research study documents clearly that there is a problem. Illiteracy does have a major impact on health, through both direct and indirect intervening mechanisms. The health of people with limited literacy skills is worse as a result.

The study indicates that there is limited awareness of both the extent of illiteracy and its impact on the health of a great many people. And even many people who have some awareness of the problem are not sure what they could do about it. Furthermore, the issue has been basically neglected by the research community. Even those with relevant data have frequently not addressed the implications of this information about the influence of illiteracy on health status. Consequently, despite increasing attention to health inequities and despite the fact that literacy underlies many other components of socio-economic status, literacy has received scant notice on the health policy agenda.

However, the study also provides some good news. Many people are aware of the connection between illiteracy and health, and are doing something about it. The study identified steps which some health workers have already taken to address the health problems associated with illiteracy, and many other potential solutions were also identified.

The research supports the need for action to combat the health problems which result from illiteracy.

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APPENDIX A

OBSERVATIONS OF COMMUNITY ORGANIZATIONS ABOUT HEALTH AND LITERACY PROBLEMS

A. BACKGROUND

A brief letter, a copy of which is attached as Appendix A-1, was sent to some 368 literacy, health and special interest groups including Ontario community literacy groups, Public Health Units, District Health Councils, francophone literacy groups, Community Health Centres, Health Service Organizations and Ontario Literacy Coalition Regional Network Coordinators.

The letter requested each respondent to comment on five basic questions:

* Are you aware of health problems that are related to illiteracy?
* If so, what specific problems have you encountered?
* How is health information acquired by people with low literacy skills?
* What approaches have been tried to provide health information to people with limited reading skills?
* What other strategies might be considered?

Who Responded?

A total of 107 responses were received. However, 7 of these arrived too late to be included in the analysis, resulting in 100 usable responses.

As Table 1, which appears at the end of this discussion, indicates, a total of 27% responded to the letter but the rate of response varied considerably across different types of organizations. For example, 65% of Public Health Units responded compared to only 18% of literacy groups.

The richness of responses also varied considerably, ranging from a few comments to several pages of personal observations and suggestions. For example, those received from Public Health Units were especially thoughtful. It was quite clear that many people had personal experience of health problems related to illiteracy and were very appreciative of the opportunity of expressing their feelings on the subject.

Analysis

The responses received were analyzed and coded into common categories. Tables 1 - 5 that follow this discussion contain a complete listing of the various categories that were established together with the exact number of responses received in each category regarding each of the five basic questions noted above.

Appendix A-2, which is attached, contains a complete listing of all the actual responses that were received in each category. All the responses appearing in Appendix A-2 are either in the form of direct quotations or as a summary of comments made.

For cross-reference purposes, note that the categories have been numbered in the same way in both the Tables and in Appendix A-2.

Although 100 responses were analyzed, note that the number of responses appearing in the Tables do not total 100 because, in some cases, more than one response was received from the same organization, not everyone answered all the questions, and many provided more than one response to each question.

Table 3, for example, contains a breakdown of the various categories of health problems reported. While these have been grouped under the headings shown, there is some overlap from one area to another and for this reason, some of the examples in Appendix A-2 appear twice.

Furthermore, the number of times a particular response is given in an open-ended questionnaire should be treated with caution. For example, just because only one person suggested a particular strategy may not mean it is not worth pursuing - others may simply not have thought about it.

B. WHAT DID PEOPLE SAY?

Does Illiteracy Create Health Problems?

As Table 2 shows, three-quarters of respondents said "yes".

Who were the six respondents that said "no"? Three were from the health area, two from literacy groups and one was a special interest group.

One example of those who didn't know or couldn't respond were a number of District Health Councils who indicated that they have no direct contact with clients. Although many indicated that they were not aware of problems themselves, they did tend to express interest in the outcome of the project.

Specific Problems Encountered

As Table 3 indicates, almost one-half of all responses referred to health problems arising from incorrect use of drugs. This type of problem is illustrated by the case of a man who couldn't read a prescription properly and gave his wife (who also couldn't read) an overdose, resulting in the need for hospitalization (twice).

Other major health problem areas mentioned included misinterpretation of health information and inappropriate use or lack of use of health services because of clients' inability to read. An example of this type of problem is the case of a young boy who fell and cut his forehead near his eye. His mother was new in town and didn't know where the hospital was and couldn't read the phone book - nor could she read parenting books and magazines.

Non-comprehension of or non-compliance with directions from healthcare professionals or improperly presented health information was another problem area mentioned frequently. For example, a diabetic couldn't - or wouldn't - use a Glu-Co-Meter to monitor blood sugar.

A somewhat higher proportion of literacy groups reported that their clients were unable to read instructions and dosages and were unable to access health and medical services. This may be because many tutors have developed a close rapport with their learners who are willing to confide in them. These same learners may be very reluctant to request assistance from health professionals and thus health care workers are not made aware of their difficulties.

While only a few respondents raised poor nutrition as an issue directly, it is apparent from the literature review and from respondents' comments regarding, for example, special diets, that poor nutrition is a widespread problem among people with limited literacy skills.

Many respondents commented on the incidence of stress, depression and low self esteem and/or alcoholism in their clients as a result of their inability to read and there were some examples of how learning to read had helped their clients to overcome these problems.

Failure to follow special diet instructions (e.g. for diabetics, after-care) was another area commented on by a number of respondents and improper infant formula preparation and administration was another widely reported health problem.

Indeed, a number of problems which were coded in various different categories related to the health of the children of

people with low literacy skills, especially babies. For example, in addition to the problems attributed to improper formula preparation, a number of children received improper dosages of medications, e.g. cough syrup, and inappropriate treatments or lack of treatments because of poor parenting skills.

Safety was also a factor that many respondents commented upon referring to their clients' inability to read signs and instructions, be aware of dangers as well as occupational risks.

Where Is Health Information Acquired?

As Table 4 indicates, most people with low literacy skills obtain health information by word of mouth - from family and friends - and from health professionals. While information obtained in this way can be very helpful, many respondents pointed out that their clients had to rely on memory to retain the information. Furthermore, information acquired via word-of-mouth is often inaccurate and health professionals are not always used appropriately as a source of information.

Only one person identified videos as a way in which people obtain health information although others indicated that they use this and other audio-visual materials to assist their illiterate clients.

Strategies - Tried and Suggested

Table 5 contains a number of suggested approaches to dealing with the health problems of people with low literacy skills -both strategies that respondents have actually tried as well as other potential solutions.

It is apparent that public health nurses do a lot of home visiting and it appears to be a successful way of assisting clients with low literacy skills. One-on-one demonstrations were mentioned many times as an effective way of getting information across. However, not many respondents suggested home visits as a strategy but that may be because they are already doing it.

The use of pictures was recommended by many people. Pictures, symbols and other visual aids seem to be most effective when used one-on-one or in small group sessions, rather than for mass distribution. Many people noted the need for simple, pictorial brochures for distribution to their clients in order to reinforce and aid memory after a demonstration or discussion.

Many respondents, too, spoke of the need to simplify the written health information that is now available as well as the need for provincial and federal health ministries to develop more readable materials.

A large number of respondents spoke of the need to make health professionals more aware of the issue of illiteracy and a number of comments were made about the need for direction in how to handle it. However, a few health professionals indicated that the issue was not a matter that they should have to deal with but rather was one that should be looked after by health educators.

Lots of people suggested TV as an approach. Others pointed out that most people with low literacy skills don't watch educational TV but are very likely to watch soap operas. Some respondents also said that TV was too confusing and that radio was a more effective method.
Finally, many respondents noted that the best strategy was in teaching people to read, to improve education and to provide adult literacy training.

Other Approaches

Several respondents referred to means of communication for the blind using braille or tape and others mentioned special telephone lines, e.g. use of hot lines.

Special Groups

Although the letter did not specifically ask about special groups, several respondents mentioned certain groups as being especially at risk, in particular, older adults, persons with disabilities, children, native people and immigrants were referred to.

TABLE 1

RESPONSES TO THE LETTER

Total Number of Responses Received: (7 late responses not included)	100 out of 368	- 27%
Health Service Organizations and Community Health Centres:	11 out of 46	- 24%
District Health Councils:	14 out of 27	- 52%
Public Health Units:	28 out of 43	- 65%
Literacy Groups:	35 out of 191	- 18%
Other:	12 out of 61	- 20%

TABLE 2

DOES ILLITERACY CREATE HEALTH PROBLEMS?

YES - 74

NO - 6

DON'T KNOW OR COULDN'T RESPOND - 22

TABLE 3

SPECIFIC PROBLEMS ENCOUNTERED

Category	No. of Responses
A. Understanding/correct use of prescription and OTC drugs:	47
1. Incorrect medication/drug dosage (prescription and/or OTC), inability to differentiate and/or knowledge of medications (26)	
2. Can't read instructions about proper use of drugs/medications (21)	
B. Inappropriate use or lack of use of health services:	41
1. Lack of knowledge about how to access services (e.g. not getting OHIP) (16)	
2. Refusing help or afraid to ask due to embarrassment over illiteracy (13)	
3. Inappropriate use of medical services (e.g. hospital emergency) (7)	
4. Waiting for health crisis, no prevention measures (5)	
C. Not receiving, understanding and/ or misinterpreting health information	36
D. Stress/depression/low self esteem/ alcoholism related to illiteracy	22

E. Lack of compliance with directions from health care professionals due to non-comprehension/misunderstanding	16
F. Therapeutic or special diet instructions not followed (e.g. diabetics, aftercare)	14
C. Infant formula preparation and administration	13
H. Safety - inability to read signs, instructions, be aware of dangers, occupational hazards	11
I. Providing and/or understanding medical consents	8
J. Learning disabilities/perceptual problems	8
K. Poor nutrition related to literacy problems	7
L. Uncorrected eyesight/small print	3

TABLE 4

WHERE IS HEALTH INFORMATION ACQUIRED?

Category	No. of Responses
A. Word of mouth, family, friends	36
B. Health professionals	22
C. Media - TV, radio	17
D. Support workers/volunteers (e.g. tutors)	10
E. No information acquired	9
F. Written information - simple English, translations, translations by family	4
G. Videos - as part of class presentation	1

TABLE 5

SOLUTIONS - TRIED AND SUGGESTED

Category	Tried	Suggested
A. Use of pictures, comics, symbols, visual aids	35	35
B. Use of simplified written information, large print, translation, adaptation, revision of written materials on health information pamphlets, instructions, etc. checking material for readability	28	38
C. One-on-one interventions or demonstrations, (e.g. home visits)	20	8
D. Videos, tapes, slides, overheads, flipcharts, audio cassettes, etc. for use with individuals, groups	17	18
E. Use of small group sessions with clients, school visits	14	10
F. Use of volunteers (e.g. tutors) to teach health information	10	7
G. Education/awareness of health care professionals and social service workers, employers, to problems of illiteracy	9	27
H. Use of TV or radio	6	24
I. Co-operation between literacy/ health groups	6	12

Category	Tried	Suggested
J. Use of workers with similar cultural backgrounds	3	2
K. Improve reading skills, encourage school attendance, referral to literacy groups	1	20
L. The "big picture" e.g. general community development, higher level policy direction	0	14
M. Other	9	7

ONTARIO PUBLIC HEALTH ASSOCIATION
L'ASSOCIATION POUR LA SANTÉ PUBLIQUE DE L'ONTARIO

APPENDIX A-1

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Making the World Healthier and Safer
For People Who Can't Read, Phase 1

We are interested in hearing about experiences and ideas from you and your organization. If appropriate, please pass these questions to your health educator or someone else in your organization for response:

1. Have you or your organization become aware of any health related problems in your clients which may be related, directly or indirectly to a lack of sufficient skills?

2. Could you please describe these to us, as specifically as possible? How do you deal with health risks?

3. How do your clients who cannot read well acquire health information? How do they deal with health risks.

4. Has your organization used any creative approached to provide health information to persons with limited reading skills? Are you aware of others who may have done so?

5. What kinds of strategies do you think might be considered?

We are interested in any ideas, however "rough" or tentative.

If you have an opportunity to discuss these questions with some of your clients and obtain their perspectives and ideas, as well as examples of any difficulties they may have faced, this would be especially helpful to us.

Please respond to the above address. If you prefer, please feel free to call Mary Breen, the Project Manager at (416) 367-3313.

Please ensure that you indicate name, position, organization and telephone number.