

Adult Learners' Perspectives on
Screening Reading Ability for Patient Teaching

by
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Thesis submitted to the School of Graduate Studies of the
University of Ottawa
in partial fulfillment of the requirements
for the degree of
Master's of Arts in Education



Sharon Brez, Ottawa, Ontario, 1995



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ISBN 0-612-15703-2

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ACKNOWLEDGMENTS

It is with appreciation that I would like to acknowledge the faculty members who provided me with support, encouragement and assistance. Sincere thanks is expressed to Dr. Maurice Taylor for sparking my interest in adult literacy issues and for providing overall guidance and supervision of the thesis. Dr. Janice Ahola-Sidaway's expertise and interest in the qualitative research paradigm and early support in clarifying methodological concerns was extremely helpful. Special appreciation is extended to Dr. Cora Hinds, of the University of Ottawa Faculty of Nursing, for offering a most valued Nursing perspective to the review and critique of my work.

I would also like to acknowledge the invaluable contribution of the research participants and literacy teachers who readily and generously shared their experience and knowledge. As well, thank you to the college administrative and support staff who graciously facilitated the recruitment and interviewing process.

Finally, I would like to express my deepest appreciation to my husband, Paul, for his sense of humour and unwavering patience and support throughout the preparation of this thesis.

ABSTRACT

The expectation of greater individual responsibility for health promotion practices and decision making in hospitals is dependent upon knowledgeable consumers. The heavy reliance on printed material for both gathering and disseminating information in hospitals has led to recommendations that literacy screening tests be considered to enhance the efficacy of patient teaching interventions for the significant number of adults with low literacy skills.

A qualitative case study design was used to investigate the response of adults with low literacy skills to literacy screening. Data were collected through in depth interviews including an experience using the Rapid Estimate of Adult Literacy in Medicine (REALM) word recognition tool. Analysis was achieved using a constant comparison technique.

A conceptual model of response to screening was developed and compared to the Health Belief Model and Knox's Proficiency Theory of adult learning. While all participants supported the principle of screening in the context of the hospital, response to the REALM experience was variable. Factors found to influence responses to screening included perceived risks of illiteracy exposure, perceived risks of non-disclosure during hospitalization and the attribution of characteristics to the hospital leading to it's designation as a "special" place. Specific responses to the REALM were found to be further influenced by a set of individual historic factors. The results have lead to several recommendations for health care professionals considering utilization of literacy screening instruments.

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CHAPTER 1

INTRODUCTION

Health care philosophies and practice are rapidly incorporating the expectation that individuals will assume increased responsibility for personal health care decision making and participation in health promotion activities. The operationalization of this expanded role is dependent upon consumers who are knowledgeable and skilled.

This trend will have a significant impact on more than thirty percent of adult Canadians who have low literacy skills. Not only does this population experience poorer health than their literate counterparts they are unable to fully benefit from the difficult print materials commonly encountered in health care settings.

Compounding this problem of reading difficulty is the increasingly heavy reliance of health care workers on print materials to both convey and gather information (Breen, 1993). Printed forms are frequently used in hospitals to gather admission information about such things as allergies, previous medical and psycho-social histories. Handouts are used to help patients make decisions about tests and

treatments and to assist in teaching patients about medications and discharge instructions. The use of standardized handouts has escalated in response to several factors including increasing legal and professional requirements to substantiate that patients have been informed. As well, realities of shorter hospital stays and increased patient acuity have placed a premium on the time available to create and implement individualized teaching plans in busy hospital settings. These practices exemplify the observation made in the Literacy and Health Project report, (1989, p.55) that most people, including many health care workers, do not understand the full extent of illiteracy in our society.

Program planning models for adult education indicate that effectiveness of educational interventions is highly dependent on accurate assessment of learner needs (Knox,1986; Long,1983; Simpson,1982). While an educator's previous experience and beliefs may inform the planning process, literacy workers, low literate learners and education experts agree that the learner should be the primary source of information and guidance when planning for educational interventions. This is especially so when assisting a population, such as adults with low literacy skills, whose needs are not well understood (Breen, 1992;

Knox, 1986; Literacy Branch, Ontario Ministry of Education, 1991).

An awareness of these environmental limitations, combined with an emerging understanding of the incidence of illiteracy and an acceptance of the importance of learner centered needs assessment to the planning of effective educational interventions, has lead to recommendations supporting the use of literacy screening tools in health care settings. Specifically, word recognition tools, such as the Rapid Estimate of Adult Literacy in Medicine (REALM) have been recommended by some as the ideal screening intervention to assist with planning for patient teaching. (The REALM is found in Appendix A). This support is based on the ease and speed of administration, reports of instrument validity, and the association of REALM results with recommendations for appropriate written resources, not with *labeling* of the individual learner (Davis, T., Crouch, M., Long, S., Jackson, R., Bates, P., George, R., Bairnsfather, L. 1991).

Issues related to adult illiteracy and literacy assessment are complex and evolving (Burnaby, 1992; Cervero, 1985). Research of these issues, especialy from the learner's perspective, is not plentiful and has not yet provided clear answers to questions about the impact of

adult literacy and literacy assessment on individuals and their life experiences, including hospitalization. The research done for this thesis will contribute a small piece to the foundation on which future consideration of these important questions can rest.

The first chapter lays out the scope and organization of the thesis. The research problem is introduced along with the research question under investigation. This is followed by a discussion of the purpose and significance of the study. In order to provide greater clarity and enhance reader understanding, as well as to facilitate replication of the study and interpretation or application of results, terms which are open to multiple interpretations or are not commonly used are operationally defined. Finally, the organization of the remainder of the thesis is described.

Statement of the Problem

Direct assessment of reading ability through the use of word recognition tests or screening tools has been suggested as a mechanism to quickly and accurately identify those patients who do not read, or read with difficulty (Davis et al., 1991; Doak, Doak & Root, 1985). Instruments such as the

Rapid Assessment of Adult Literacy in Medicine (REALM) have been developed for this purpose and are currently being used in hospital settings (Davis et al., 1991). While the knowledge gained through direct assessment may enhance the efficiency and effectiveness of educational interventions, there is divergent opinion in the literature and among expert health and literacy practitioners regarding this practice. It remains unclear how potential learners will respond to direct assessment of their reading ability for the purpose of planning health teaching. Some believe this approach may be shunned by poor readers resulting in diminished self esteem and self-efficacy which may create barriers to learning. Others believe that this direct approach will be well accepted and may relieve learners' anxiety about receiving incomprehensible materials resulting in improved self-efficacy towards learning necessary skills and knowledge.

People routinely expose their physical and psychological weaknesses in the hospital based on their desire for improved health and the presumption of a high level of confidentiality. As such, this may represent a privileged setting or "special case" where those with poor reading skills feel less vulnerable exposing their literacy limitations. More study of this complex situation, from the

learner's perspective, is required to enhance the knowledge base for clinical decision making.

Purpose and Research Question

The purpose of this exploratory study was to gain an understanding of the response of English speaking adults with low literacy skills to screening of reading ability in order to facilitate the planning of patient teaching in a hospital setting. The Rapid Estimate of Literacy in Medicine (REALM) was the screening tool used to provide a literacy screening experience for study participants, hence specific response to the REALM was also investigated.

In other words, the study sought to answer the following question: How do adults with low literacy skills respond to assessment of their reading ability, using the Rapid Estimate of Adult Literacy in Medicine tool (REALM), for the purpose of planning patient teaching in a hospital setting?

Significance of the Study

The frequency, impact and complexity of adult illiteracy and its negative effect on health, make it an issue of special importance for health care educators. Over

the past five years federally, provincially and privately funded surveys have clearly and consistently demonstrated the incidence of illiteracy in Canada. One recent survey indicated that 17% of English speaking adults had severe difficulty using print materials for any purpose and a further 21% had some difficulty unless it was simple, clearly laid out and required little manipulation or interpretation (Jones,S., 1992).

As the significance and implications of illiteracy become increasingly evident, providing educational opportunities which improve access to information for those with poor literacy skills is emerging as an important focus for health care educators. Societal trends to increased consumerism, collaborative decision making in health, the proliferation of home based health management technologies such as capillary blood glucose testing for diabetes management and peritoneal dialysis for treatment of renal failure, along with the realities of shorter hospital stays have heightened our concerns about the relationship of low literacy to health. Recent surveys underline this concern, indicating that those with lower education and literacy abilities report poorer health status, greater activity limitations, more frequent use of prescription medications and hospital emergency facilities and higher rates of

accidents (Breen, 1989; Ontario Ministry of Health, 1992).

A screening tool such as the Rapid Estimate of Adult Literacy in Medicine (REALM), which is valid, quick to administer, easy to interpret, directs the user to appropriate teaching strategies and is accepted by patients would be extremely beneficial for hospital use. It could lead to enhanced efficiency, more appropriate use of teaching resources and improved patient outcomes.

Very little, if any, research has addressed the learners' perspective on direct literacy assessment or screening for the purpose of planning patient teaching (Burnaby, 1992). When studying this potentially vulnerable population, literacy researchers, adult educators and literacy students have strongly recommended approaches which are learner centered (Burnaby, 1992; Ontario Ministry of Education, 1991).

Merriam and Simpson (1989) have noted that case study methodology "leads to an increased understanding of the phenomenon by clarifying concepts, generating hypotheses, or constructing explanatory frameworks" (p.90). This approach to qualitative investigation has been recommended as particularly appropriate for use when there is little knowledge about the problem or in the investigation of new topic areas (Eisenhardt, 1989; Merriam and Simpson, 1989).

Based on these recommendations, a case study, qualitative methodology has been used in this research to gain a better understanding of the feelings, attitudes and reactions of low literate learners to literacy screening and the paradigm from which these responses emerge.

The knowledge gained through this research has enriched the understanding of learner response to the intervention of literacy screening for patient teaching. The dissemination of this information may contribute to more informed clinical decision making and practice by those assisting patients to meet their learning needs.

It is also hoped that this study will strengthen the theoretical understanding of adult learning. While theories of learning from the fields of psychology, sociology and education have frequently been cited in the patient teaching literature the sampling processes and data collection methodologies have often excluded those with limited literacy skills. The use of difficult language, printed questionnaire format, lack of perceived relevance and inaccessibility of low literate adults as subjects may have contributed to this observation.

In this research the Health Belief Model and Knox's Proficiency theory have been compared to the substantive model that emerged from the data analysis. The process of

comparing the emergent conceptual model to existing theoretical frameworks enabled identification of several similarities providing evidence upon which the extension of existing theory to those with low literacy skills may be considered.

Assumptions

The assumptions underlying and hence guiding this research are based on those proposed by Lincoln and Guba (1985) in their description of the naturalistic paradigm. They have been identified as supportive of and congruent with several qualitative methodologies, including case study research. The assumptions underpinning this research included the following:

The nature of reality

There is no one truth explaining human experience. Realities are constructed by individuals and are multiple. They can only be understood when first examined holistically (Lincoln and Guba, 1985, p.37).

The interaction of observer and observed

The researcher and subject continually interact and in so doing influence one another in a process of mutual shaping. As a result, each interaction is unique and never

totally reproducible (Lincoln and Guba, 1985, pp. 37, 318).

The case against generalizability

The aim of an investigation is to develop a hypothesis, model or substantive theory which describes a particular case or set of cases. Predictive, positivist laws are not consistent with explanation of human behavior (Lincoln and Guba, 1985, p. 38).

The influences of values

Values influence all inquiry and are associated with the researcher, the subject, the method, the context and the paradigm guiding the investigation (Lincoln and Guba, 1985, p. 38).

The human as data collection instrument

The human instrument is capable of fully responding and adapting to indeterminate situations as arise in examinations of human response. Humans can sense and respond to personal and environmental cues and interact with the situation to make its dimensions explicit. The human as instrument is capable of a high level of trustworthiness (Lincoln and Guba, 1985, pp. 193, 195).

The Sources of meaning

While it is possible to explain and describe most of what we know through verbal language, non-verbal signals also communicate meaning. This results in a 'sense', 'feel'

or 'intuition' of meaning referred to as tacit knowledge. Tacit knowledge is gained through experience and rumination or reflection. It is a valued, legitimate and unique property of human communication which enriches understanding (Lincoln and Guba, 1985, p. 195).

Operational Definition of Terms

The terminology used in literacy and health education has been defined in a variety of ways and several terms have been used to describe the same phenomenon. For the purpose of this study the following terms were operationally defined as follows.

Functional illiteracy: The state of an individual who does not possess the reading skills necessary to use print material commonly encountered at work, at home or in the community, including the hospital. This term has been used synonymously with the definition of functional illiteracy put forth in the Survey of Adult Literacy in Ontario (Jones, S., 1993). A common or precise definition of illiteracy is not available nor may it be desirable. Judgments of the quality of reading ability vary based on the context of the situation and the values or beliefs about

literacy held by the evaluator (Cervero,1985). It is therefore the responsibility of each writer to describe the parameters used to define terms related to illiteracy. In this study it has been assumed that English speaking adults, enrolled in adult basic level communication classes at a community college, with reading skills judged by the college through the use of standardized reading tests to be less than those normally associated with completion of grade nine, were poor readers. The terms low literate, functional illiterate and poor reader have been used interchangeably in this paper.

Adult: An individual of a least 18 years of age, deemed capable of independent decision making.

Reading Screening: Assessment of basic, primary reading skills using a word recognition or comprehension tool or instrument in order to broadly categorize reading ability. The assessment referred to is not at a level required for diagnostic purposes, but rather at a level sufficient for preliminary determination of an estimated range of reading ability in order to select appropriate teaching methods or resources.

Patient Education: A planned learning experience, using a combination of methods, intended to influence an individual patients' knowledge, skill or health behaviors related to specific circumstances. May be used synonymously with patient teaching (Jenny, 1993).

Organization of the Thesis

Chapter two of the thesis contains a selected review of pertinent literature from the domains of adult education, literacy, nursing and health promotion which informed this study. Literature which was reviewed during the data analysis phase of this investigation has been integrated into the later sections dealing with interpretation and application of results.

Chapter three includes a brief discussion of case study methodology followed by a description of the actual methodology, design, sample and the instrumentation and data collection techniques used in the research.

The fourth chapter provides readers with an opportunity to hear the voices of the research participants. Reports of the thoughts, feelings and actions of the participants as individuals and as a group are presented, analyzed and interpreted. This analysis is used to support the model

building that is presented in chapter five.

Chapter five presents a conceptual model of response to literacy screening along with a comparison of this new model, grounded in the research findings, to two existing theories of adult learning the Health Belief Model (Rosenstock, Stretcher and Becker, 1988) and Proficiency theory (Knox, 1980).

Chapter six, the final chapter, provides a summary review of the study and a discussion of the implications of the research to clinical practice and suggestions for future investigations.

CHAPTER 2

REVIEW OF THE LITERATURE

An overview of selected literature which impacted the development of the research study is presented in this chapter. A discussion of the role and timing of the literature review in research undertaken using the qualitative paradigm prefaces the review which guided and supported the study. As no previous research was found that addressed the specific problem under consideration, that is the response of low literate adults to literacy screening for health teaching, related literature was reviewed in order to provide the necessary background to appreciate the scope and implications of the research problem. Topics presented in this chapter include the incidence of adult illiteracy in Canada and its relationship to personal health; trends in health promotion philosophies and practice and their impact on those with low literacy skills; issues concerning literacy assessment, noting the technical, social and philosophical nature of assessment; as well as a brief discussion of the role of educational theories in the research.

Qualitative Methodology and the Literature Review

The function of a literature review in research guided by the qualitative paradigm has been debated in the literature and there remains a lack of consensus regarding its purpose and timing. As a result, it was felt that a brief discussion of the role of the literature review should be undertaken early in this chapter in order to assist the reader in appreciating the scope of the review that follows.

While some have postulated that the naive researcher represents the ideal state for unbiased collection and analysis of data undertaken within the qualitative paradigm this approach represents a minority position. The very act of human experience and existence would seem to make this an unrealistic expectation (Eisenhardt, 1989).

Considerable support was found, however, for consideration of the literature at various temporal points in the research for a variety of purposes (Leininger, 1985; Lincoln and Guba, 1985; Mitchell and Cody, 1993; Sandelowski, 1993; Wolcott, 1990). Early in the study the literature review might be used to identify theoretical gaps or inconsistencies indicating areas requiring further research. The review might also suggest or justify the use

of particular methodologies. Wolcott (1990) recommended two specific times for reviewing the literature, an early review of the literature to "nest" the topic and again later in the study after data collection, noting that "the most appropriate place for examining the literature seems to me to be in consort with the analysis of new data"(p.17).

Sandelowski (1993) suggested two other important purposes for reviewing the literature later in the study. A kind of triangulation might be achieved through the comparison of conceptual models which emerged from the data with existing theories related to the phenomenon under study. Finally, she noted that "theoretical formulations may also provide schemas for re-presenting findings in a research report" (Sandelowski, 1993,p.217). While this approach requires considerable care to maintain the integrity of the meaning of the findings as presented by participants it allows for the testing or extension of existing theory. As well, the use of established terminology to describe comparable phenomena facilitates the accumulation of a body of knowledge which may help move existing conceptualizations towards theory.

After careful consideration of these viewpoints it was decided that an early review of the literature was justifiable and in fact necessary to answer some preliminary

questions raised by the problem being investigated. It enabled verification of the significance of the research question and sensitized the researcher to some of the social and cultural issues related to low literacy which might impact the methodology and instrumentation. The following questions guided the initial literature review.

- 1.What is the incidence of illiteracy in Canada? Is it a big enough problem to worry about?
- 2.How does illiteracy influence health?
- 3.What approaches are currently being used to teach hospitalized patients? How accessible is health promotion information to those with low literacy skills?
- 4.How might literacy screening impact patient teaching?
- 5.Are there social forces that might influence the response of poor readers to literacy screening?
- 6.What are the current thoughts about adult literacy assessment and how might these apply to health care settings and patient teaching?
- 7.Are there existing theories of learning cited in patient teaching literature that have been applied to teaching those with limited literacy skills?

While these questions were most helpful in confirming the worthiness of the topic for investigation, identifying

gaps in existing research, and guiding methodological decisions they represent only a portion of the literature that informed this study. In accordance with the recommendations of Wolcott cited earlier, the literature search and review process was reintroduced after data collection and preliminary analysis. This information has been woven into the applicable sections throughout the thesis.

Incidence of Illiteracy

Over the past few years major federal, provincial, and privately funded surveys have clearly indicated the incidence of illiteracy in Canada (Breen, 1989, 1992; Jones, S., 1992; Ontario Ministry of Health, 1992; Southam News, 1987). These studies were all based on variations of a "functional" definition of illiteracy, linking it to the information processing skills needed to use commonly encountered printed material in everyday contexts, such as work, home and community. Burnaby (1992) noted that there have been some questions raised about the interpretation of the results of the Southam study based on the definition of illiteracy used and the nature of the assessment methods employed. The similarity of the Southam (1987) findings with

those of the later Canadian Survey of Literacy Skills Used in Daily Activities may minimize these concerns. This 1989 survey, part of a major study sponsored by National Literacy Secretariat, Multiculturalism and Citizenship Canada, included interviews and literacy testing results from 9,500 adult Canadians. The assessment of literacy included not only measurement of reading ability but also incorporated a qualitative assessment by the participants themselves.

Jones, S. (1992) summarized and interpreted the Ontario results from this study. He found that 9% of adults in Ontario had difficulty dealing with printed material and would most likely describe themselves as unable to read while 8% could use print material for only limited purposes and would describe themselves as having difficulty with common reading material. A further 21% could effectively use printed material only when it was simple, clearly laid out and data manipulation was not complex. This last group tended to avoid situations requiring reading, even though they had some ability. These findings supported the earlier Southam Literacy in Canada survey (1987) which reported an estimated 24% of adult Ontarians required help with reading, writing and using numbers and as such were classified as functionally illiterate. The Ontario figures closely mirrored those found at a national level.

Competence, experience and social context have been cited as factors which influence literacy ability (Burnaby, 1992). Cervero (1985), in his article devoted to discussion of the possibility of a common definition of illiteracy noted that "literacy is defined in the context of a given environment, different contexts require different skills"(p.52). In the unfamiliar context of the hospital setting it is, therefore, reasonable to expect that the number of people who are functionally illiterate will be increased. Medical and technical terminology frequently used in hospitals is not commonly heard in daily discourse. It is often difficult to read and pronounce and the concepts referred to are unfamiliar to much of the population. Individuals who may be considered literate in their usual social context may become functionally illiterate in the hospital environment.

Dilemmas in Survey Interpretation:

Blaming the Victims?

Discussions of ethical and moral dilemmas related to the interpretation of survey results and the development of health care philosophies and policy shifts were noted in the literature review. While the surveys consistently indicated

the high incidence of illiteracy, caution in the interpretation of the meaning or significance of these results might be indicated. It has been suggested that recognition of the incidence of illiteracy has lead to the use of alarmist, accusatory terminology by groups including the press, government, business, health care and educational institutions (Jones,P.,1991). While the use of inflammatory language may be effective in stimulating public interest and government action this terminology may also encourage the laying of blame, shame or guilt upon individuals with low literacy skills if they are perceived as the source of the problem.

The report of the Canadian Business Task Force on Literacy estimated the cost of illiteracy to Canadian business and society as a whole to be in the many billions of dollars (Jones,P.,1991). Askov and Aderman (1991) reflected the economic impact and focus of illiteracy in their description of literacy training "as an investment in developing human resources to meet the labor market needs of business" (p.11). In times of economic instability this clear linkage of illiteracy to economic inadequacies may perpetuate the "blame laying" on individuals with low literacy skills.

This issue was also discussed by an eminent group of

literacy and education experts invited to participate in the 1991 national symposium "Issues and Options in Literacy" sponsored by the Ontario Ministry of Education. A concern was expressed "that literacy would be seen as only an issue of international competitiveness and that literacy practice would get distorted as an economic rather than a rights issue" (Ontario Ministry of Education, 1991,p.83). They noted as well, the need for the achievement of a balance between the understanding of illiteracy as an economic issue and recognition of it as one of social welfare, associated not only with business or government impacts but also with community and individual needs.

While warnings have been sounded about the potential implications of broadly interpreting survey results without consideration of the negative impact on individuals, there are others who have seen the recognition of a high incidence of illiteracy as a positive factor. Increasing awareness may provide opportunities for change that will help those with limited reading skills. An enhanced understanding of the incidence and experience of low literacy may serve to sensitize those in the service professions, including health professionals. According to Mintz and Steele (1992) this sensitization will lead to better assessment of learner needs, and tailoring of educational interventions to meet

these individual needs.

Illiteracy and Health

Low literacy levels are evidently associated with poorer health, a situation reflected in both the literature reviewed and in conversations with health care professionals. People who have only primary education, most of whom were assumed to be functionally illiterate, experienced more health problems than the average Canadian and used hospital emergency departments more often (Ontario Ministry of Health, 1992). They also reported feeling a sense of poorer personal and social well-being than their literate counterparts. These findings were attributed to two main factors, the direct impact of inability to read on understanding printed material and the lower socio-economic status often associated with lower education and limited reading ability.

Anecdotal incidents of misuse of medications leading to tragic results and misadventures related to inability to follow instructions or directions demonstrated the direct relationship of illiteracy to health (Breen, 1992). Examples of the impact of illiteracy on health abound and provide a clear picture of the significance of this problem. Hussey

and Gilliland (1989) recounted the story of a young, pregnant woman who was prescribed antiemetic suppositories for nausea relief. When she returned to the clinic reporting no relief the nurse discovered that the suppositories had been swallowed. This patient had not had previous experience with suppositories, she was unable to read the instructions and she did not ask for assistance. The authors suggested reasons for not asking may have been related to concerns about hiding her illiteracy or to a lack of appreciation of the existence of any route other than oral based on information limited to her own life experiences. This narrower perspective imposed on those unable to read, impacts interpretation of meaning and recognition of the possibility of alternatives (Doak et al.1985; Hussey,1991; Hussey and Gilliland,1989).

A recent article in a local paper described an example of the potentially tragic results of illiteracy. A young mother, with limited literacy skills, had just returned home with her new baby. In the hospital she had been feeding her baby prediluted formula but at discharge she had unknowingly purchased concentrate with a similar label. As a result of her inability to read the instructions on the label, she prepared the formula as instructed in the hospital. The infant received concentrated formula for several days and

died. Possessing knowledge and understanding instructions is a necessary step in enabling compliance. When printed materials are used as the main mechanism for providing information, those with limited literacy skills are likely to be negatively impacted (Spees,1991).

Patient Teaching Resources and Literacy

Health care professionals have indeed come to rely heavily on written materials as the primary method for both disseminating and collecting health information. Time constraints, lack of awareness of the extent of adult illiteracy, desire to provide standardized information and the need to comply with institutional and legal requirements related to informed consent have all contributed to the perpetuation of this practice. This reliance has been extensively documented in the literature as has the high level of reading difficulty of printed materials available in hospital settings. Most material commonly used requires at least high school reading ability (Baker, Newton, Bergstresser, 1988; Belton,1991; Breen,1989,1992,1993; Jackson et al.,1991; Meade, Deekman and Thornhill,1992; Powers 1988; Spees,1991; and Streiff,1986). These findings concerning high readability were found to apply to a wide

range of instructional materials from consents for treatment or surgery to information about tests and therapies and instructions for medication administration.

Materials cited in the literature as difficult to read have not only been those produced in-house by institutions for local use but have also included resources produced professionally by major health promotion agencies such as the American Cancer Society and the American Academy of Dermatology (Baker et al,1988; Meade et al,1992). The reading difficulty of many available resources clearly did not match the reading abilities of a significant proportion of the intended audience. Streiff (1986), suggested that "a great deal of time and energy expended on the part of both practitioners and patients may be spent in vain"(p.48), if poor comprehension is, in fact, a major cause of failure to achieve the desired results of patient teaching.

On a more positive note, there appeared to be an increasing awareness of low literacy as evidenced by the large number of studies addressing this issue. At the level of national organizations, such as the American Cancer Society, repeated review of the reading difficulty of resources over time indicated that attempts were being made to produce printed materials which were easier to read (Meade et al.1992).

Changing Health Promotion Philosophies

Health care philosophies in North America have undergone significant change in the past decade. These changes will impact those with low literacy skills. Health care philosophies are rapidly moving away from a traditional, paternalistic imbalance of power and authority in favour of health care professionals to one of increasing equity for consumers. Knowledge, authority and responsibility are being given to the patient transforming their role from passive recipient to active consumer. Jenny (1993), noted "the goal of patient/health education is empowering people to control their own behavior in order to improve their health status, functioning and quality of life"(p.1410). Further, she contended that individuals will be expected to participate more actively and collaboratively in an environment "where educator and client share the responsibilities for desired outcomes".

Salsberry (1993), writing from the American viewpoint agreed, noting a trend towards a change in emphasis to an expanded role for health care consumers with increased responsibility for personal health care decisions. She argued that "this kind of choice is possible only when the

individual is informed of the inherent risks, is competent to make the decisions and the decision is voluntary"(p.213). While Jenny (1993) suggested that this philosophical shift was occurring in response to pressure from a better educated society who desired this change, one must wonder about its impact on those with limited education or literacy skills.

This move towards increased consumer participation and responsibility has seemingly been embraced by legislative groups, social and consumer action supporters, and some health care philosophers (Jenny, 1993). Support, however, does not seem unanimous as voices debating the moral and ethical implications of this philosophical shift are beginning to be heard.

As Salsberry (1993) suggested, allocation of responsibility can be linked to laying blame and fault. In the case of those with limited social, educational, intellectual, physical or economic resources or skills or for those who lack access to information, choices for action may not be optimal because, in fact, no real opportunity for choice exists. Limited knowledge, resources or skill may have so constrained choices that responsibility for outcomes is not fairly allocated to the patient. Accordingly, Salsberry (1993) recommended "that a health reform package that assigns liability must provide individuals denied

resources in the past to follow healthy lifestyles with additional services to improve their health in the future"(p.216).

Becker (1993), in his comments upon accepting a distinguished service award from the American Sociology Association, addressed many of the same concerns regarding the growing responsibility shift for health promotion. His comments supported Salsberry's contention that many factors influence an individuals ability to make free choices and as such these factors, whether social, political or economic should not be ignored as major impacts on health promotion.

Concern regarding the possible repercussions of changes in institutional and political attitudes toward health promotion was evident in the literature. Whether supporting or challenging the new health promotion philosophy strong opinion was evident amongst health care providers, literacy experts and sociologists. Supporters of expanded consumer roles and responsibilities appeared to be responding to the needs and desires of well informed, educated, articulate individuals. This philosophical shift may reflect a lack of consideration or understanding of the potential impact of social expectations and policy changes on nearly 30% of the adult population who have difficulty

accessing or applying information.

Assessment of Adult Literacy

No research was found that directly addressed the question of poor readers response to assessment of their reading ability using the REALM tool, and only a very few addressed assessment of reading ability for patient teaching (Belton, 1991; Doak et al., 1985; Jackson et al., 1991; Murphy, 1993; Spees, 1991; Streiff, 1986). This was not surprising due to the focus on assessment for purposes other than placement in literacy training programs, the lack of awareness of the prevalence of illiteracy and the traditional silence of illiterate learners. The search was therefore broadened to consider a variety of methods and views on illiteracy assessment. Assessment approaches considered in this section include self-reports, grade equivalencies, and word recognition tests.

Self Reports

It has been established that self reports of reading ability and highest grade completed are often not valid indicators of actual reading ability. (Bristow and Leslie, 1988; Jones, 1992; Hussey and Gilliland, 1989).

It appears that highly literate individuals, such as health care professionals, operate from different cognitive paradigms than those who are less literate. The understanding of "adequate" or "good" reading ability of those with low literacy skills differs from that of highly literate individuals. The Survey of Adult Literacy in Ontario (1992) indicated that of those who demonstrated the lowest abilities, 52% rated themselves as moderate to good readers, and of that same group, 88% reported that they were satisfied or somewhat satisfied with their ability to read. In the context of their own families and communities many of these individuals were not perceived as poor readers. This study also found that 55% of those who recognized themselves as having difficulty reading also stated they had reading skills adequate for daily life. Disturbingly, almost half of this group were unable to use the bottle label to determine the correct Aspirin dose for a seven year old when they had to find it in the midst of instructions for other ages.

Bristow and Leslie (1988) stated that "poor readers must experience serious disruptions of text before noticing there is a problem". Part of the reason for the lack of congruence of self reports and actual ability may be related to their finding that adult poor readers are less likely to

consider reading a comprehension task and more likely to view it simply as a decoding process. In other words, reading was related to speaking words, not to understanding them.

It has been suggested that those with little experience using information presented in written format may have limited ability to organize their thoughts and perceptions according to the way content is presented in written text. The use of headings, lists, numerical sequencing, abbreviations or incomplete sentences may interfere with comprehension (Hussey, 1991). This assessment is echoed by Meade (1992), who noted that "the ability to read influences ones understanding and interpretation of meaning as well as ones thoughts, perceptions and ability to analyze instructions"(p.53).

When these unintentional causes for unreliable self reports are coupled with intentional attempts to cover a limitation which may be perceived as socially undesirable, it becomes evident that this approach is unsatisfactory for determining reading ability.

Formal Assessment: To Screen or Not to Screen?

Since simply asking people does not produce the desired information, two alternative approaches have been

recommended for assessing reading ability for patient teaching. One involves direct assessment using screening tools (Askov and Aderman, 1991; Doak et al, 1985; Spees, 1991), the other indirect assessment (Breen, 1992).

Some, including literacy experts, have not supported direct testing methods (Breen, 1992; Finlay and Harrison, 1992). Instead, they have suggested informal methods including observation for subtle clues of reading difficulty such as avoidance of written material and non-participation in learning opportunities. While the importance of matching educational interventions to learner's needs was well appreciated, concern was expressed that identification of illiteracy through screening might result in labeling and stigmatization of the learner. (Breen, 1992; Fiske and Taylor, 1984; MacGinitie, 1993).

In a similar vein, Beder (1991) specifically examined stigma and literacy. He used Goffman's definition of stigma as "the situation of an individual who is disqualified from full social acceptance". It was found that illiteracy carried such a stigma, with poor readers often stereotyped as "unproductive, stupid, chronic failures, socially dependent and morally deficit"(p.67).

Conversely, direct assessment has been supported as an efficient and expedient method to improve the efficacy of

patient teaching efforts. Some proponents of this approach have recommended several methods of formal assessment from grade equivalencies to comprehension testing and screening using word recognition tests.

Grade Equivalencies

Grade equivalency refers to the practice of estimating a persons reading ability based on the number of years of formal education completed. Grade nine has frequently been used as the point above which literacy was assumed and is the cut point used by UNESCO in defining functional illiteracy. This point has been used in assessing both reading ability and readability levels of written text but the correlation of these qualities with the school grade completed is less than perfect (Streiff, 1986).

In 1981 the International Reading Association recommended that those who administer standardized reading tests abandon the practice of using grade equivalents to report performance of either individuals or groups of test takers (Farr, 1986). A grade equivalent is just a test score which has little meaning until it is interpreted. One might rightfully ask, what does grade nine reading ability really mean? As there is no common national curriculum the actual reading ability associated with completion of nine years of

schooling is likely to be extremely inconsistent.

Word Recognition Tests

Word recognition testing has been cited as a mechanism to consider when an imprecise, broad assessment of reading ability is required. Support is based on the apparent efficiency and expediency of some of the tools developed for this purpose and the assumption that word recognition is predictive of comprehension (Streiff,1986). Proponents of this approach have recommended that word recognition tools such as the frequently used Wide Range Achievement Test (WRAT) or the newly developed Rapid Estimate of Adult Literacy in Medicine (REALM), be used as indicators of reading ability (Davis et al.,1991; Doak et al.,1985; Jackson et al.,1993; Meade et al.,1992; Murphy, Davis, Long, Jackson and Decker,1993; Streiff,1986).

No supported accounts of learner response to these tools was found in the studies which utilized them for screening purposes. Apparently those who have used these approaches have made the assumption that learner participation in screening activities indicated acceptance or satisfaction with the process. (Davis et al.1991; Doak et al.,1985).

Word recognition has been supported as a valid

indicator of adult reading ability by Bristow and Leslie (1988) and Doak et al. (1985). The term 'word recognition' has several meanings in the reading assessment literature. It may mean the translation of print to speech either phonetically or by instant recognition, the recognition of the meaning of printed symbols or a combination of both (Farr, 1986).

Most word recognition tests are based on the assumption that recognition is predictive of comprehension. According to Bristow and Leslie (1988) research in assessing children's literacy has shown this association, however they note that few studies have been done to validate these findings in adults. It was postulated by these researchers that adults might utilize different cognitive processes in reading and that psychological factors, such as previous negative experiences with reading, might lead to a decreased sense of self efficacy, negatively influencing reading performance. Poor adult readers "relied heavily on their general knowledge and made excessive use of context in figuring out text, even when contextual knowledge was low and decoding skills would have been more helpful" (Bristow and Leslie, 1988, p. 203). This study concluded that oral reading accuracy played a strong role in predicting comprehension in moderate to difficult text and

substantiated the importance of verbal word recognition in enabling adequate comprehension. They also found that slow rates of word recognition and lack of automaticity was positively related to decreased comprehension capacity. While word recognition may be a necessary first factor for comprehension it may not be sufficient. Farr (1986) reminds us that there is an inadequate understanding of adult reading theory, and little research has been done using poor, adult readers as subjects.

The literature on reading assessment appeared to demonstrate a trend away from reliance on scored tests to assess literacy (Jongsma and Farr, 1993). MacGinitie (1993,p.559) summarized much of what is expressed in the literature as follows: "Since our assessments are fallable and limited the decisions based on them should be tentative....We should stop thinking about assessment as a way of making categories and start thinking of assessment as a way of making opportunities". Others reflected this trend towards a more humanistic approach to adult literacy assessment. Peers (1993) contended that for adults who need to learn content it is important that assessments support positive learning and low emotional risk. This was echoed by Finlay and Harrison,(1992) who suggested that informal methods that look as little as possible like tests may be

the best. The feelings of the individuals participating in the assessment may significantly influence results, "no matter how well designed from a cognitive perspective a test is, it will fail to give an accurate picture if the human subject isn't in a fit shape to take it" (Finlay and Harrison, 1993,p.167). The emotional or social impact of the testing experience itself may significantly influence the participants performance and hence the validity of results.

Despite an indication in the literature that literacy testing has lost some popularity as a diagnostic procedure, reading specialists continue to support its use for screening or as a mechanism to select appropriate learning strategies (Jongsma and Farr,1993; MacGinitie,1993).

While consensus on the use of word recognition tools for literacy screening was not found, their use was supported on several fronts. Practicing educators, health care workers, literacy experts and educational measurement specialists were among those accepting this strategy for screening purposes when the intended outcome was the selection of appropriate teaching interventions rather than diagnostic labeling.

It seems that particular care is required in administering and interpreting the results of screening

tools. If perceived as tests, these interventions have the potential to cause learner anxiety which may negatively influence the results. As well, and perhaps more importantly, the literature indicated that learners may be perceived negatively if they are identified as poor readers and exposure of their limitations may create anxiety or impact self esteem.

The literature did not provide a clear indication of response to screening from the learner's perspective. Those studies which discussed this point of view at all were related to reading assessment in educational settings. The response to screening in the context of health care settings was not addressed and will be the focus of this investigation.

Learning Theory, Literacy and Patient Teaching

The role of theory in qualitative research has been debated in the literature. It is apparent that theory may be considered at a variety of times for a variety of purposes. In this research study a survey of patient teaching literature was undertaken prior to the data collection to determine if theories of learning had been used in patient teaching research involving subjects with low literacy

skills. Locus of Control, Learned Helplessness, Social Cognitive Learning Theory, the construct of self efficacy and the Health Belief Model have frequently been used in well designed investigations of patient teaching and health promotion but rarely, if ever, has the study sample been representative of poor readers. Only one reference was found that attempted to link a learning theory, Locus of Control, to low literacy and patient teaching. The source was a short review article which speculated on the relationship of locus of control and low literacy skills to compliance with care prescriptions (Hussey and Gilliland, 1989).

The previously reviewed literature on literacy assessment suggested that this population may have special learning needs based on the relatively isolated perspective imposed by illiteracy, the incompatibility of their learning styles with the heavy reliance on printed resources used in health care settings and the social impact of illiteracy on self esteem and self concept. As a result, caution has been suggested in generalizing the findings of existing patient teaching literature to those with low literacy skills (Hurley, 1992; Hussey and Gililand, 1989; Merritt, 1989; McDermott, 1993).

As mentioned at the beginning of this chapter, care must be taken to minimize the effect of preconceived

theoretical orientations on the data collection and analysis. With this in mind and upon reflection on the advice of several qualitative methods experts, (Merriam and Simpson, 1989; Mitchell and Cody, 1993; Wolcott, 1990), it was decided to postpone further review of learning theory literature until completion of data collection and analysis. A discussion of theories of learning that were considered particularly relevant to the findings is found in chapter five.

In summary, it is safe to say that issues concerning adult literacy are complex and not yet well understood. While this review has addressed the questions concerning adult illiteracy, literacy assessment and patient teaching posed earlier in the chapter, simple, clear answers were not always found. The incidence of adult Canadians who have difficulty reading and understanding printed materials commonly encountered in their every day lives was found to be high. For many of those individuals, low literacy appeared to have the potential to negatively impact their health. This negative impact may be compounded by a growing reliance on printed materials for disseminating information to patients in hospital settings, further limiting this populations access to health promotion information.

Changing paradigms of health care, trends towards

increased patient participation in home based self care regimes and participative decision making, all require knowledge commonly obtained through reading. These changes, therefore, present a significant challenge to those with limited literacy skills and may in fact promote further marginalization of an already vulnerable population.

A diversity of opinion concerning adult literacy assessment philosophies and strategies was noted in the literature reviewed across the domains of education, adult literacy and patient teaching. Despite recommendations that the perspective of adults with low literacy skills inform investigations intended to enlighten the understanding of literacy issues it appeared that this point of view has not frequently been sought. Clearly, a learner centered, qualitative approach was supported for use in research aimed at exploring phenomena related to adult illiteracy.

CHAPTER 3

METHODOLOGY

Chapter three opens with an introduction to case study methodology and a discussion of its applicability to the research. This is followed by a brief description of the pilot study which was undertaken in preparation for this investigation. The remainder of this chapter has been dedicated to describing the specific methodology used in the research. Considerable attention has been given to issues of sampling reflecting its importance to the interpretation and reliability of case study data. Based on information obtained in the literature review, a novel approach was used to gain consent. As well, special consideration was given to the construction of the interview guide in order to facilitate understanding and participation by those with limited literacy skills. These sections may be of particular interest to readers undertaking future research involving similar participants. A discussion of the method used to analyze the data concludes this chapter.

Case Study Design

A qualitative, case study methodology was used for this research. This methodology has been recommended when a rich, full understanding of a previously under studied, complex and sensitive phenomenon is desired (Lincoln and Guba, 1985). Merriam (1988), suggested use of the case study method when the researcher is interested in "insight, discovery and interpretation" of particular events or phenomena while Eisenhardt (1989) and Yin (1984), recommended this method when description and theory generation are desired. The aim of the study, to gain an understanding of the response of adults with low literacy skills to reading assessment for patient teaching, is congruent with the criteria for selecting a case study approach.

Case study methodology may be used for investigations of single or multiple case design. Multiple case design has been used in this research. Yin (1984) contended that the evidence from multiple cases enhances the robustness of the study and may create a more compelling description or explanation of the phenomenon under investigation. Multiple cases can be considered, according to "replication logic", to be analogous to multiple experiments rather than just

multiple subjects within one experiment (Yin,1984,p.48). This argument was supported by Eisenhardt (1989) when she described initial data analysis as occurring within cases not only across cases.

The principles guiding case study methodology have emerged from a variety of qualitative traditions and as a result are very similar to those guiding many types of qualitative analysis (Eisenhardt,1989; Lincoln and Guba,1985; Tesch,1990; Yin,1984). The principles which guided this research included the following:

1. Analysis of data is an iterative process occurring concurrently with data collection. This analysis informs subsequent data collection and case selection. In case study design this involves detailed case write up for each participant to allow for familiarity with each case as a stand alone entity (Eisenhardt,1989; Tesch,1990).
2. Sampling is purposeful and directed by ongoing data analysis. Attempts are made to sample a range of case characteristics in order to identify contradictory evidence. Cases are selected which are likely to replicate or extend the emerging conceptualizations (Eisenhardt, 1989; Goetz and LeCompte,1984; Yin, 1984).

3. Case selection is determined when the point of redundancy is realized (Eisenhardt, 1989; Lincoln and Guba, 1985; Sudeman, 1991).

4. The data collection and analysis are not usually guided by a predetermined theoretical framework, rather the data analysis leads to the development of a conceptual model or theoretical understanding of the phenomenon under investigation. This conceptualization is facilitated by recording analytic notes on the reflective and concrete process (Eisenhardt, 1989; Tesch, 1990).

5. Data are divided into units of meaning. These may be single words, phrases or summaries of verbal expressions of an attitude or acts. While this segmentation occurs the researcher must take care to maintain a sense of the "whole" by initial and ongoing reflection on the case through transcript and audio tape review (Tesch, 1990; Yin 1984).

6. Analysis is achieved through constant comparison of data units and organization of these units into representative categories or themes. Categories of data are generally derived from the data themselves with evolving themes emerging through an inductive process. Comparison and

contrast is the mechanism used to establish categories, sort data and find negative cases or patterns within the data. The human investigator is the primary instrument for data collection and analysis (Eisenhardt, 1989; Lincoln and Guba, 1985; Tesch, 1990).

7. Data categorization is flexible and modified to accommodate the data presented within each case. It is appropriate to look at data many ways and modify categories accordingly to the best "fit" with the data (Spradley, 1980; Tesch, 1990).

8. This process is intended to result in a description of structure, model of patterns or interactions or synthesis of concepts into constructs or substantive theory (Eisenhardt, 1991; Tesch, 1990; Yin, 1984).

The Pilot Study

The pilot study for the research was undertaken three months prior to the main study. The small pilot was designed to mirror the study, using an easily accessible, small sample. The purpose of the pilot was to reveal any design inadequacies and to familiarize the researcher with

salient issues or sensitivities relevant to interviewing participants with limited reading skills which might influence methodology or researcher approach in the main study. It was undertaken as part of the requirements for fulfilling an advanced level graduate course in adult education. This provided an opportunity for valuable input and critique from both mentors and colleagues experienced in the fields of adult literacy and patient teaching.

Two subjects, aged 40 and 50 were asked to participate based on their consented referral by an individual who had previous experience in the development of literacy training programs. Both subjects had experience along the adult literacy continuum from non-reader to their current ability to read simple, clearly presented information. Participants were selected based on their interest in participation, their experience as adults with limited literacy skills, their familiarity with the hospital as patients and their willingness to provide criticism to the study process.

The pilot provided confirmation that the semi-structured interview guide included questions that were well accepted by participants and yielded the quantity and quality of data desired. The consent was well understood and participants responded appropriately to questions stating they were able to understand what was being asked and

reporting that they felt comfortable with the questions. One item was removed from the original schedule due to the redundant nature of responses to it. The simulation experience provided an opportunity for the researcher to see evidence of the potential vulnerabilities that may be exposed by the experience. The participants were able to discuss feelings related to the screening experience and recommended strategies for minimizing potential participant discomfort. The pilot experience also provided a very valuable opportunity for the researcher to practice using plain, clear language in conversation. The participants supported the proposed site for recruiting main study participants as well as the proposed selection criteria for the study.

The responses of the pilot participants to literacy screening for patient teaching using the REALM were very articulately and candidly presented. These cases were not included in the data analysis of the main study, however, their responses provided substantiating evidence which was later compared to the findings. While many benefits were accrued from conducting a pilot, the researcher remained ever wary of the potential for allowing these preliminary findings to influence future data analysis. A very conscious effort was made throughout the main study to consider the

data separately and to purposefully challenge any interpretation of data for the presence of preconceived bias. In effect, the researcher played the role of devil's advocate with her own interpretations throughout the study.

Sample

The sample for this research was purposely selected, as recommended in the literature (Eisenhardt, 1989; Goetz and LeCompte, 1982; Lincoln and Guba, 1985; Sandelowski, 1989). The initial selection criteria included: fluent English speaking adults; previous patient experience and low literacy skills representing as broad a range of adult illiteracy experience as possible, considering the resources available for the study. Fluent English speakers were selected since it was felt that they were more likely than non-English speaking adults to have literacy limitations overlooked in the busy health care setting. As well, based on Beder's findings related to the stigma associated with literacy exposure and the attempts of those with low literacy skills to hide their limitations, it was felt that those who possessed low literacy skills in a language in which they had verbal proficiency would likely respond more intensely to literacy screening (Beder, 1991).

The sensitive and often hidden nature of adult illiteracy created a challenge in locating and recruiting potential participants. Not only was the topic difficult to discuss the whole notion of research was alien and threatening to some members of this population. Based on recruitment experience of the pilot study and discussions with literacy experts it was recognized early in the study that there would likely be few people willing to candidly discuss their experiences with low literacy.

Eisenhardt (1989) noted that it makes sense to choose cases in which the "process of interest is transparently observable"(p.537). As a result it was decided to approach a local community college in Eastern Ontario for assistance. This institution offered basic level adult education classes for those wishing to upgrade their literacy skills in order to pursue higher education, retraining or simply to learn the skills necessary for everyday living. Gaining permission to address these students in the classroom setting provided a much larger pool of potential study participants. This group had already indicated an appreciation of their limited literacy skills by virtue of their enrollment in the program, and had already accepted a degree of risk related to low literacy exposure.

The college was very supportive of the study and the

faculty were identified as expert consultants and gate keepers. The students placed considerable trust in their teachers, to the extent that demonstration of teacher awareness of the research activities, and support of the researcher herself, became a strong predictor of the likelihood of student volunteers. This required deliberate care by both teachers and the researcher not to put any pressure on students to participate and the provision of several opportunities for reconsideration of withdrawal from participation without repercussions.

Both voluntary and "reputational" case selection strategies were used to recruit participants (Goetz and LeCompte, 1984, p.82). With permission from the program director, the researcher attended six literacy classes to explain the project. These classes contained both native English speakers and those for whom English was a second language and were specifically selected to represent a broad range of reading abilities from beginner readers up to grade 10-12. Students were assigned to classes based on communication skill ability. Approximate reading ranges associated with each communication class level were as follows: Level 1, up to grade five; level 2, grade 6-8; level 3, grade 9; level 4, grade 10-12. Potential participants were given the opportunity to volunteer at that

time, to contact the researcher at a later date or to leave their name with their teacher if they wished to participate or desired more information. College faculty and study participants were also asked to facilitate reputational selection by identifying and recruiting representative, articulate individuals. It was hoped that these initial informants might have been able to recommend potential participants who had not yet enrolled in literacy training programs or "gone public" with their illiteracy. Seidman (1988) described this as the "snow-balling" technique. While many participants stated that they knew people in this situation no participants referred them to the study. This was interesting as they were very ready to recruit classmates but demonstrated a solidarity in their respect for the confidentiality of others they knew with low literacy skills who had not "gone public".

As Goetz and LeCompte (1984) note, sampling in this methodology is dynamic, phasic and sequential, hence the number and characteristics of subjects was determined as data were collected and analyzed.

Attempts were made to sample a broad range of reading abilities. Literacy ability was determined by the college assessment and classroom placement, REALM results, and participants description of their own ability. No attempt

was made to determine exact reading level, as this degree of specificity was not required, nor was it possible. An awareness of broader ranges of ability was sufficient for this study. This approach was discussed with literacy experts and teachers and was supported by them.

Eight individuals participated in the study. Five volunteered as a result of classroom information sessions, two were recruited by fellow students and one particularly articulate participant who had previously expressed an interest in speaking about his illiteracy experience was recruited by a teacher. Participants stated that they had volunteered for a number of reasons including a desire to share or profile illiteracy issues, interest in the novelty or perceived eliteness of participating in a research project and an interest in health promotion and the potential to improve hospital experiences for others with low literacy skills. Three others who had initially agreed to interviews were lost to the study. Two had left the school program and the researcher was unable to contact them. One potential participant stated that she had simply reconsidered. The researcher assumed that the anticipated sensitive nature of the discussion of literacy screening may have contributed to this withdrawal.

Participants ranged in age from 21 to 55, the group

consisted of an even number of males and females and represented a wide range of reading abilities and experience from virtual non-readers to those nearing completion of high school equivalency.

While the number of subjects was small, the data were rich. After eight interviews it was clearly evident that themes were recurring and no new categories of information related to the response of participants to literacy screening were emerging. These signals indicated that the point of redundancy had been reached (Lincoln and Guba, 1985; Seideman, 1991).

Data Collection

According to several authors (Merriam, 1988; Polit and Hungler, 1987; Yir, 1984) case study methodology does not claim any one, specific method for data collection or analysis. Eisenhardt (1989) noted that case studies may include a single data collection strategy or may combine several methods of data collection, including participant observation, interviews, questionnaires or archival data. As the study population was unable to utilize written material easily, interviews and participant observation were the strategies used for data collection in this research.

The interview offers both potential strengths and weaknesses as a data collecting technique. It may provide the best mechanism for getting to know what participants think, feel or believe and frequently yields data that would be difficult to find otherwise (Polit and Hungler, 1987). The interview process provided an opportunity to understand the participants, allowing meanings to be clarified and verified on the spot. Reflecting back interpretations for verification provided an ongoing credibility check.

On the other hand, there may be legitimate concern about the validity and accuracy of information shared during an interview. Both the participant and the interviewer influence the quality of responses. Steps to minimize interview bias, as suggested by Polit and Hungler (1987) and Yin (1984), were applied to this research. Participants may bias results by rushing responses to get things "over with", answering in a manner aimed at pleasing the researcher, or avoiding discussion of difficult, sensitive, conflicting or minority points of view. Authenticity of responses may be assessed by consideration of the interview climate and motives for participation, searching for contrary or conflicting responses within the case and assessment of the willingness of participants to discuss potentially sensitive or controversial opinions. As well, the genuineness of

responses may be indicated by the consistency of non-verbal communication with what is said and willingness of participants to be recontacted for clarification or verification.

A semi-standardized interview guide was developed based on the preliminary literature review and conversations with literacy and health experts, literacy educators, and poor readers themselves (Appendix C). As reported in an earlier section, this guide was evaluated in a small pilot study. The results of this effort indicated that the questions were easily understood and well accepted by participants and they appeared to yield quality data.

While some would recommend the use of unstructured interview in qualitative case study design, a more structured approach was purposely selected for use with this population. It provided a framework that allowed subjects with low literacy skills, unfamiliar with the generalizations and conceptualizations often developed through reading, to understand and feel comfortable with the questions being asked. Broad, open questions may have been perceived as vague, confusing and irrelevant by non-readers. They could have been interpreted as an indication that the individual asking them had no knowledge about the field of inquiry and might have undermined the researcher's

credibility with this population (Doak, Doak and Root, 1985). The semi-standardized schedule allowed the researcher to add questions for clarification or fuller understanding and to explore new avenues of inquiry. While some questions were quite specific many were worded to be open enough to allow participants the opportunity to reveal personal feelings and thoughts about the research topic.

During each interview, subjects were asked to participate in a simulation exercise, using the REALM tool. (Appendix A). After participants had an opportunity to reflect and speak about past hospital experiences, the researcher, who was also a nurse, administered the REALM as it would be done for the purpose of planning patient teaching. The administration instructions provided with the REALM were adhered to (Appendix B). This exercise permitted observation of participant reactions to REALM administration and provided an experience using the REALM that participants could respond to verbally.

Simulation experiences have been recommended as appropriate strategies for gaining preliminary information about responses when no previous data have been reported (Fraenkl and Wallen, 1990). Goetz and LeCompte (1984), in their review of types of questions appropriate for use in qualitative interviews, included role playing, simulation

and hypothetical questions that encourage speculation. The use of a simulated REALM experience, administered by a stranger, who was known to be a nurse, was assumed to closely reflect a hospital screening situation. The participants were, theoretically, all potential patients who could have been hospitalized at any time.

The literature indicated that reactions to literacy screening, in the context of health teaching is not known. Some speculated that this intervention might be viewed by patients as beneficial while others suggested the potential for negative responses. In light of the potential negative impact of literacy screening and in consideration of the absence of substantiated findings to the contrary, it was felt that the use of a simulation experience would provide valid data without risking the possibility of compounding the stress already experienced by patients dealing with hospitalization and illness.

Each interview was preceded by an informal, individual or classroom group information session aimed at initiating a rapport between the researcher and potential participants. This initial conversation was followed by a telephone call or conversation with individuals who had indicated an interest, explaining the study in more detail, and asking them to participate. The timing and location of the

preliminary conversation and interviews were mutually selected considering the comfort and privacy of the participant. While a variety of on and off campus sites, including the participants homes were offered, all participants chose to be interviewed at the college. A private office had been made available to the researcher for this purpose. Participants found that the direct hallway access to the office and it's location afforded them both convenience and privacy. All but one interview occurred in an office setting, the exception, at the participants request, occurred in an empty classroom. In all cases care was taken to arrange the chairs in a friendly, informal manner around a table other than a desk. This facilitated observation of non-verbal responses by both participant and interviewer and diminished any positional suggestion of power imbalances within the relationship.

As was anticipated from the pilot study, the formal interviews lasted between 20 and 110 minutes, averaging about one hour. All interviews were audio recorded. Immediately after each interview notes were written about the non-verbal observations, the tone of the interview, the interviewers thoughts, feelings and intuitions about the interaction and the perceived authenticity of the participant.

Consent

At the beginning of the interview an easy to read question and answer style information sheet was given to each participant. The researcher had previously piloted this form with low literate adults who had indicated good comprehension of the content and indicated that it was "clear and easy to read". The use of this question and answer format, written in informal, conversational tone, was recommended by Doak et al.(1985) as a strategy appropriate for presenting novel information to learners with low literacy skills. This information was also read aloud to each participant by the interviewer and questions for clarification were encouraged.

The content covered all aspects required to enable informed consent to be granted. A simplified consent form, recommended by an Ontario Program Based Research Special Interest Group in their guidelines for doing research involving participants with low literacy skills, was used to gain written consent (Appendix D). Permission to tape record the interviews was also requested and pseudonyms were used to maintain confidentiality.

Data Analysis

Content analysis using a constant comparative technique was employed in the study. Interview content and observation notes were reviewed and reflected upon immediately following each session, and transcripts reviewed on an ongoing basis. Using the researcher as data collection tool required the continued consideration of personal bias during data collection and analysis. Information was reviewed in context, meaning units relevant to the research question were identified and coded, manually sorted, categorized and checked in an attempt to develop a valid understanding of the issue. Besides developing categories which inductively arose from the data, the researcher used Spradley's categories of cultural domains to assure that categorization of data was not constrained by researcher bias or lack of creativity. Spradley has developed a typological framework of categories of cultural meanings that may occur in any social situation (Spradley, 1980). Meaning units used in the research were phrases of text or sections of observation notes describing complete thoughts, feelings, attitudes or actions.

This simultaneous process of data collection, analysis

and verification was seen as essential for the identification of modifications required in sampling and interviewing to validate or expand the emergent understanding. As well, this process allowed increased intimacy with the data contained in each case and facilitated management of large volumes of information (Sandelowski,1989; Eisenhardt,1989).

A cross case search for patterns was coupled with the within case analysis. While a computer program might have hastened the categorization of data, the researcher found that manual cutting and sorting of meaning units, and shuffling them to form and test categories, as suggested by Wolcott (1990), provided visual cues which facilitated the model building and theory development in the study. As tentative conceptual categories were developed the iterative process continued, constantly comparing meaning units to existing concepts creating new, discrete categories as required.

The researcher remained cognizant of the risk of 'leaping to conclusions' based on hunches or feelings not supported by the data. Confirmation of findings was achieved through tabulation of data in a matrix fashion according to case and content as evidenced by meaning units taken from the transcripts and case notes (Eisenhardt,1989; Yin,1984).

Colour coded dots were used to indicate commonalities and differences across cases. This juxtaposition of data clearly demonstrated patterns and provided a method of triangulation by data sources (Yin,1984). Once valid categorization and relationships were determined a typology and conceptual model was developed to explain the findings.

Trustworthiness

Research undertaken in the tradition of the qualitative paradigm has been based on assumptions which are inconsistent with the positivist understanding of validity and reliability (Eisenhardt, 1989; Forchuck and Roberts,1994; Lincoln and Guba, 1985; Yin,1984). Constructs more consistent with these methodologies have been developed to judge the quality of results. Lincoln and Guba initiated use of the term "trustworthiness" to describe the four characteristics of qualitative methodology analogous to validity and reliability: credibility, transferability, dependability and confirmability. Yin has considered similar characteristics and attempted to describe them under the traditional titles of validity and reliability.

Trustworthiness has been achieved in the research through consideration of the following constructs.

Credibility

This term has been compared to the traditional concept of internal validity. This has been achieved in several ways. A combined field journal and personal log was maintained. Entries were recorded immediately following each interview and notes made upon reflection. The setting and tone of the interview, nonverbal responses and observations of participants were noted along with introspective notations about the state of mind of the researcher in relation to the interview experience. Developing constructions, and understandings of relationships among data categories, as well as points requiring further clarification, were also recorded. This provided evidence of the development of a chain of logically linked evidence. It also allowed the researcher to maintain enhanced objectivity in data interpretation, identifying potential researcher bias.

Member checking was utilized as a mechanism to enhance credibility. During the interviews unclear or unexpected responses were reflected back to participants to ensure an accurate understanding by the researcher. As a typology and model were developed, key participants were asked to verify the researcher's interpretation of the data. Triangulation

by sources (Lincoln and Guba, 1985; Yin, 1984), or comparing the degree of congruence of responses between the participants and the literature was also employed after data from all cases were analyzed. Finally, the application of replication logic to the eight individual cases was carried out. Initial analysis of data within each case prior to analysis across cases supported and strengthened the credibility of the findings (Yin, 1984).

Transferability

This construct represents the ability of the researcher to provide sufficient range and quantity of information to allow "someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility" (Lincoln and Guba, 1984, p. 316). Since no individual or context is exactly the same retest to confirm results is not possible. The user of qualitative research can only judge the applicability or transferability of results to their situation based on the descriptive accounts of the process and findings provided in the study text. Attempts have been made to facilitate transferability through the provision of an introduction to the participants and descriptions of the interview environment and local characteristics of the community in which the study took

place. As well, selected quotations from all participants have been included to explain and provide evidence supporting the findings.

Dependability and Confirmability

These have been grouped together to reflect the qualitative equivalent to reliability. Description of the research process through the development and reporting of the case study protocol has been provided in detail sufficient to allow another researcher to replicate the study. While it has been assumed that the findings will not be identical due to variations in researcher and participants that naturally occur across time and context, adequate description has been provided to allow for meaningful comparison of results across studies. This will provide other investigators the opportunity to challenge, support or extend the understanding of the phenomenon being investigated.

Limitations

As with any study involving a small number of participants it is not possible to generalize the findings of this research to all adults with limited literacy skills.

While attempts were made to sample broadly according to variations in gender, age and reading ability, participants reflected a degree of homogeneity based on their attendance at community college communication classes. Some may view this inability to produce a broadly generalizable model as a limitation while others contend that the intimacy with the data allowed by small sample case study research is a methodological strength. The likelihood of a valid conceptual model arising from the research is very high because the model building is so closely tied to the evidence (Eisenhardt, 1989).

The location for the research may have influenced participants response to literacy assessment. The study was conducted in a "government" city where white collar employment was prevalent and education levels exceeded the provincial average. As adult illiteracy was not generally considered a common condition in this community, feelings of vulnerability related to low literacy exposure and hence response to screening, may have been uniquely impacted.

As well, the researcher as data collection tool possessed characteristics which may have influenced findings. Although the researcher was clear in informing participants that this investigation was being undertaken in the researcher's capacity as a graduate student in education

they were also told that she was a nurse. It is possible that this influenced the quality of results obtained if participants felt increased comfort and trust speaking about sensitive, personal issues with a health care professional.

Finally, the use of a simulation experience was assumed to closely reflect a hospital screening situation. While the literature has supported the use of this type of activity to assess participant responses it may raise questions about the transferability of findings to an actual hospital setting.

CHAPTER 4

FINDINGS AND DATA ANALYSIS

In this chapter participants will be introduced and the findings reported according to the categories or themes which emerged from the interviews. The researcher has followed Yin's (1984) recommendations for "writing up" the findings from case study research. While a section has been devoted to introducing participants, individual case analysis is not reported as a block of data. The report has been constructed to present cross case analysis for both descriptive and explanatory purposes. Each section has been devoted to a specific cross case theme with information from individual cases dispersed throughout the section to lend support or further explain the phenomenon being discussed. This method of data presentation facilitated analysis and theory building. Yin has noted that this is an appropriate format for both explanatory and exploratory case studies, for exploring causal arguments and debating the value of further investigation of hypotheses or propositions (Yin, 1984,p.129). Data analysis has been integrated with the data reporting since ongoing interpretation of findings

actually occurred concurrently with data collection.

Introducing the Players, Setting the Scene

This study has provided a voice to a group rarely heard. It offers a privileged glimpse of life experiences from a vantage point not often seen, that of the adult with low literacy skills. The participants have shown bravery in their risk taking during the study and have shared thoughts and feelings which are often hidden from the literate world. They have discussed aspects of their life experience which are often considered vulnerabilities or confidences including personal and family illnesses, interactions with the health care system and the impact of low literacy skills on these experiences. Every effort has been made to assure that the data analysis is true to their experiences and it is hoped that readers will begin to gain an understanding of the significance and impact of illiteracy exposure in the hospital setting.

A brief profile of each participant, in the order of their recruitment into the study, is provided to help acculturate the reader. Jeff, Luz, and Jan were interviewed during the first week of data collection. Jeff, a native Canadian, was the first male interviewed. An articulate, 21

year old, he volunteered publicly during the classroom information session. His placement in a level 3 class indicated reading ability in the early high school range. Jeff reported two hospitalizations in the two years prior to the interview. His responses were quick, short and spontaneous demonstrating a degree of bravado. He described a social and familial milieu where low literacy was a fairly common and accepted occurrence. The researcher hypothesized that his confidence speaking about literacy issues may have been related to the superiority of his literacy skills relative to the norm of his community.

Luz, a 28 year old single woman, was attending college classes to upgrade her writing and reading skills. She spoke English well with a bit of a Spanish accent, however, the researcher had no doubt that Luz's confident demeanor and sophisticated vocabulary would have lead to the assumption of literacy. Luz was enrolled in a level 2 (grade 6-8) communications class. She had had one previous hospital experience and was scheduled for surgery one month after her interview.

Jan, a classmate of Luz and the youngest female participant, was very bubbly and a bit naive. She aspired to a career in nursing and was upgrading her literacy skills in order to apply for professional training. This participant

expressed considerable confidence in her current reading ability and classroom progress. Jan had been hospitalized for surgery two years earlier, at the age of eighteen and had recently been involved in the care of her totally illiterate grandmother during hospitalization. Jan stated that she saw participation in this research as an opportunity to help others who might be hospitalized and to share her interest in health care with the nurse researcher.

As may be noted, the initial participants were all quite young. In order to strengthen the understanding of this phenomenon, and in a search for contradictory cases, it was decided to attempt to recruit older subjects. This led to the inclusion of Carol and Frank.

Carol, like many of her classmates in the program, had returned to school as a result of workplace retraining requirements following an injury or layoff. She had several previous hospitalizations, both recent and distant, and related her motivation to participate to an interest in "being involved in research". When the selection criteria was described she eagerly interjected "that's me!, when can we talk?" Carol, a 48 year old, had raised her children to adulthood and despite little formal education had been successfully employed until a recent injury had forced retraining. She was enrolled in a level 2 communications

class (grade 6-8 range) and described her progress as slow.

Frank was the only participant who was recruited directly by a teacher based on her knowledge of the research study and previous discussions in which Frank had indicated a desire to share his literacy experiences. As with Carol, Frank had entered the college program reluctantly, as a result of retraining requirements imposed by an insurance company following workplace injury. At the age of 45, his experiences with the health care system had been multiple and varied.

Frank was identified as a key informant. He was completing the basic program and had made unusually fast progress from virtually no literacy skills to grade 12 equivalency within the previous eighteen month period and he was planning to proceed to post secondary studies. Besides being articulate, reflective and candid in his responses, Frank was able to present the unique perspective of an adult who had recently been illiterate and was now an accomplished reader. By virtue of this transition he could more easily identify the differences in his experiences along the literacy continuum. While Frank had, in the past, gone to extreme lengths to hide his illiteracy at the time of his interview he had reached a point where he was proud of his accomplishments. He expressed hope that sharing his

experiences and insights, however difficult that would be, might eventually help others with limited literacy skills. Frank's interview was the longest and the researcher sensed it was the most reflective.

Susan was the sixth individual interviewed. While she expressed an interest in participating she missed the first two scheduled interview sessions due to conflicting responsibilities as a single parent. Susan continued to declare her interest in participation and on the third attempt, almost four weeks after the initial meeting, the interview took place. Susan wished to participate in the study because she believed her limited literacy abilities had negatively effected her hospital experiences and she hoped to be able to improve conditions for others. She was, however, very concerned about exposing herself publicly and was unsure about using her last name on the consent form. Once it was clearly established that her real name would not be used she spoke candidly and with passion about her hospital experiences and her response to literacy screening.

Susan was enrolled in a level 1 communications class (less than grade five reading ability) and possessed the most limited literacy skills of any participant. Despite obvious intelligence, several discussions were required before she really understood the purpose of the research.

Doak et al.(1985) noted that patients with very limited reading ability may have a narrow perspective on issues, reflecting their own direct, personal experience. This may be evidenced by a tendency to believe that everyone understands a situation the same way as they do. This resulted in an initial expectation that the researcher would accept Susan's concerns and as a nurse, act on them immediately to effect change in the health care system. Only with further explanation and discussion did Susan appreciate the purpose of the research and the indirect and distant potential for influencing practice in health care settings.

Concurrent discussions the researcher had with an experienced adult literacy educator indicated that this narrow perspective, and hence difficulty understanding the purpose of research, was common to this population. He anticipated that it would be particularly difficult for the researcher to recruit from this group and cautioned that those with minimal literacy skills might not possess the language or abstract reasoning skills to participate in, or discuss responses to, the simulation exercise using the REALM. Accordingly, the insight and articulate verbal expression evident in Susan's participation was a pleasant surprise. The impact of illiteracy on this woman's hospital experiences was powerfully communicated. While Susan had

experienced hospitalization herself she chose to recount the story of the impact of her literacy limitations on the surgical experience of her three year old daughter.

After the first six interviews it was becoming increasingly clear that certain themes were being repeated and few new concepts related to literacy screening were being introduced. The researcher, however, had some concerns that there was an under representation of male participants potentially preventing observation of the effects of gender on the findings. This concern about gender distribution in the sample, supported by a statement by Frank that "men have it harder than women because of this Macho thing", led to the search for more male participants.

Six weeks and thirteen site visits had passed since the initial entry of the researcher into the school setting. The researcher was recognized and received friendly acknowledgment from both teachers and students and no longer felt a stranger in their midst. Despite this growing familiarity recruiting was still not an easy process. In light of the fact that some students had been absent on summer vacation, and after consultation with teaching staff at the college, a decision was made to reapproach a small class of predominantly male students. Over the subsequent week the final two participants volunteered and were

interviewed.

Jack was the eldest participant at 55, and was also at school to upgrade his basic skills in order to find new employment after a workplace injury. He was enrolled in a level 2 communications class (grade 6-8). Jack was very thoughtful in his responses and appeared more relaxed and less intense than many of his peers in recounting the effect of low literacy on his hospital experiences. Unlike many other participants, such as Frank, Gord, Susan and Carol, Jack viewed his limited literacy ability as the normal consequence of the social situation of his youth rather than a personal inadequacy. As a young man growing up on a farm in rural Quebec it was common for the eldest son (Jack) to leave school at grade eight to help his father on the farm. As a result, many of the men Jack knew growing up and many of his peers had limited reading skills. His motto about illiteracy was "you can't go crying over spilt milk, and there's no use pretending because you're just fooling yourself".

Gord was the last to be interviewed. Interestingly, like three other participants he not only had past hospital experience but he was awaiting readmission within the upcoming month. Unlike Jack, Gord came from a highly literate family. While he had excellent vocabulary skills which he

attributed to listening to family conversations, he claimed he was unable to understand what he attempted to read and "hated" reading. He described himself as the only one in his family with reading problems and noted that he had often gone to great lengths to hide his reading limitations and avoid embarrassment. While he was placed in a level 3 communications class (grade 9), Gord described himself as a poor reader who lacked confidence in his reading ability. Gord, married with a young family, was also a thoughtful, serious participant during the interview.

The researcher believed that a rapport was achieved with each participant along with a degree of trust that encouraged open, honest responses. Only in Jeff's case did the researcher feel that initial responses were somewhat flippant and superficial, and it was not until after the simulation experience that more genuine responses were shared. Several individuals specifically commented that the researcher helped them feel comfortable, demonstrating a caring, supportive demeanor. All readily agreed to follow-up discussions with the researcher as required.

Results and Interpretation

Five major themes emerged from the data. These included:

1. risks of illiteracy exposure and ways to minimize illiteracy exposure
2. risks of non-disclosure during hospitalization
3. characteristics of hospitals as "special" environments
4. supportive responses to the concept of literacy screening for patient teaching
5. mixed reactions to screening using the REALM tool

Risks of Exposure and the Stigma of Illiteracy

This section will include discussion of two closely related themes, the perceived risks of illiteracy exposure in normal social contexts and the strategies participants have used to minimize these risks. As the intended outcome of literacy screening is the identification of an individual's reading ability it is extremely important to understand what illiteracy exposure means to those with limited literacy skill.

All participants described exposure of their literacy limitations as a risky situation. While the degree of perceived risk varied, most described it as a significant

risk in powerful and poignant terms. Only one, Jan, described illiteracy exposure in the context of normal social interactions as other than an intensely negative experience. A young participant, until recently dependent upon her family, Jan described it as "a problem which you have to solve, if you keep it in it can't be solved, if you tell someone it might be solved". She did, however, describe the situations of illiterate friends and relatives and commented that most of them would not talk freely about their reading problems except to a few trusted others and they often actively hid their reading limitations.

The other participants articulated risks of illiteracy exposure including negative impacts on self esteem, self concept, social acceptance, independence and perceptions of family role proficiency so clearly that their own words have been used to describe these themes.

Susan: I don't tell anybody or say anything to anybody, they might think I'm a bad person... If I'm given something to read which is too hard I feel bad or embarrassed.

Gord noted that he felt "extreme embarrassment" when he was younger because he "didn't want to look stupid" but at the age of 38 he found illiteracy a bit easier to discuss as he had come to realize that his situation was not unique. He

still would not volunteer information about his reading noting: "I would need to be approached directly about this...If I think someone thinks I should understand (what I've read) and does not specifically invite questions I will not ask. This was echoed by Luz:"If I had a problem I would be embarrassed, shy."

Frank described a long history of hiding his illiteracy:

Since I was 10 or 12 years old I was just ashamed I couldn't read or write, I'd never admit it, I'd do anything to cover to up...I was willing to give up anything rather than admit it.

I've seen me not go to the doctor knowing I might have to read. A few different times I needed minor operations and stuff like this. I put them off knowing that I needed them and each time I put them off to the very last minute rather than go because you're helpless. You depend on other people (When you can't read).

It's hard to put into words the feelings, the fear that someone else will find out and the person probably, more than likely, won't care, but you're afraid.

Participants expressed concern that illiteracy exposure might negatively influence their social roles or cause other people to re-evaluate their status as competent adults. Four participants discussed incidents linking low literacy to the role of competent parent. Some described hiding their illiteracy from their children or pretending in social settings to maintain the image they felt society expected.

The risk to self concept was evidenced by statements such as these:

Frank: Because of this macho thing, the image that I'm weak, you feel it, like I can't ask for help because I'm a man.

I'd pretend to read to look good, I'd just take the forms, hold them up for a few minutes and hand them back and put my signature on it.

Carol: When my daughter was in school I used to go to the school PTA meetings. They were talking all those educated words and I sort of agreed along with them even though I really didn't have a clue what they were talking about but I sort of bluffed my way through it.

It was so embarrassing for awhile, but I'm not the only person that's illiterate, now (after entering the basic education program at the age of 48) it seems like an everyday sort of thing. I used to be afraid that people would laugh at me

The most extreme impact on self concept was expressed by Susan. Near the end of the interview, after the tape recorder was turned off she quietly asked "Do you think you can tell if a person can't read by looking at them?" she felt "they could tell for sure". As extreme as this response may seem to the reader it echoed a statement heard in the pilot study for this research when a participant stated "they just look at me and they know I can't read...it was like it was showing, sort of thing."

These comments reflected low self esteem and poor self concept associated with low literacy. Fear and embarrassment

led to avoidance of situations where the risk of literacy exposure was considered high and pretending was used to avoid social ostracism.

These findings were consistent with the findings presented in Beder's (1991) work on the stigma of illiteracy. He described this as the situation of individuals disqualified from full social acceptance, stereotyped as unproductive, stupid, chronic failures, socially dependent and morally deficit (p.67). The responses of participants such as Carol and Frank, indicated that the poor readers in this study were aware of this stigma and did indeed attempt to hide their illiteracy.

Beder identified two strategies used by poor readers to avoid identification, "passing" and "covering". Passing involved pretending to be "normal" while covering required avoidance of situations where others might discover the illiteracy, or reliance on a few trusted individuals to cover and act as "readers". Several participants identified individuals who served as their readers when they were hospitalized such as wives or parents while others discussed how they, themselves had acted as readers to help less literate relatives with day to day literacy problems.

The strength of the negative response to illiteracy exposure appeared to be directly related to the degree of

risk perceived. Neither age nor gender appeared to consistently differentiate the degree of perceived exposure risk however the findings suggested that the felt "normality" of low literacy as a social condition reduced the severity of the perceived risk. Those such as Jack, Jan and Jeff, from families or communities where low literacy was more common seemed to use less extreme means to hide their limited reading abilities. Carol related a similar moderation of response after attendance at literacy classes.

Attendance at literacy classes not only improved the language skills of participants it appeared to have promoted the realization that their situation was not unique and provided a positive experience of social acceptance by the literate community. Notwithstanding, Frank noted that "old habits die hard" and when faced with difficult print materials requiring action, such as a hospital consent forms, he reported reverting to the covering and passing behaviors used as protective mechanisms in the past.

These findings led the researcher to speculate that perceived risks of illiteracy exposure and the associated negative responses, as might be triggered by screening, would be even stronger in individuals with low literacy skills who had not "gone public" through participation in literacy training programs. This was further supported by

the reluctance and refusal of study participants to refer friends or relatives with limited literacy skills to this study reflecting a deep respect for the confidentiality of undisclosed illiteracy.

Risks of Non-disclosure During Hospitalization

At the same time as discussing the risks and potential costs of illiteracy exposure participants identified risks and potential costs associated with non-disclosure of illiteracy during hospitalization. These two phenomena, apparently existing in a state of dynamic tension, were evident in every interview.

Participants spoke of both emotional and physical costs of non-disclosure during hospitalization. Frank noted that exposing literacy ability is still hard in the hospital but "it helps you get some of the worry aside". While Luz would not volunteer information about her illiteracy in most situations, in the hospital she thought "maybe I would ask...Yeah, because I don't want to make mistakes, especially in the hospital". When asked if health care professionals should attempt to determine if patients could read even if this might cause embarrassment she responded "Yeah, I think so, it's better not to sign something you don't understand and then have problems".

Jack described concern about his ability to understand consents:

I find it's the words they use on some of those diseases, you don't even know what they're talking about. You don't even know what it is but you know you don't have it because you would've recognized the word.

Jack relied on his wife or hospital staff to read and interpret for him. While he described this dependent role as uncomfortable, he felt it was "better to get help than to sign something you don't know what you're signing." Others would not risk asking for help and as a pilot participant so poignantly stated: "A lot of times I thought, my God, am I signing my life away...what am I signing?"

Worry and powerlessness were described by Carol as consequences of illiteracy in the hospital, "I'd feel intimidated quite a bit, I'd wonder how long they would be, what's going on....it's hard". While these feelings may be felt by most hospitalized individuals they are likely amplified for those with more limited access to information resulting from limited literacy skills.

Susan, told the story of a surgical experience she had had with her three year old daughter. She described the fear, anger, dependence and guilt this experience caused her. She recounted being given incomprehensible information about the surgery and signing a consent even though she did

not understand what was written. According to Susan her daughter developed life threatening complications during surgery and was left with facial deformities requiring reoperation. She described the role of her limited reading skills in the situation as follows:

That's what put me in trouble for my daughter....I still feel guilty about it. I have to look at her face and I say, why did I go through with that operation? If I had known what was going to happen to her face....I didn't know what kind of risk was involved....I almost lost her during the surgery.

While the participants initially described the discomfort of disclosure, like Susan, they also clearly spoke of the risks of non-disclosure. The consequences of lack of information and the resultant susceptibility to physical danger, and the powerlessness related to insufficient information to participate knowledgeably and competently in care decisions was evident. There was unanimous agreement that doctors and nurses should know how well patients can read and use this knowledge to plan appropriate ways to provide information that would allow a more active role in decision making.

Jack summarized the sentiments of the others. He described the risk:benefit analysis he used to deal with this contradictory situation. In the hospital context the perceived risks of non-disclosure outweigh the risks of

disclosure, "you have to choose the lesser of two evils...this one (lack of information) might kill you and this one (exposure) might not."

Study participants clearly desired a degree of control over their situation and were not satisfied with a dependent role. These findings are contrary to those of Waterworth and Luker (1990) who described patients as "reluctant collaborators". They concluded that patients preferred a passive role, trusting health professionals to make decisions about their care and treatment. Care givers were viewed by patients as powerful due to their knowledge and access to information, and control over comfort measures and even life sustaining resources. While patients willingly transferred decision making responsibility to health professionals this power imbalance was found to potentiate feelings of vulnerability. In this sample, passive, non-questioning behavior was described as "toeing the line" (Waterworth and Luker, 1990, p.971). It was considered necessary for designation as a "good" patient and was exhibited as a means of assuring access to high quality care.

There were, however, other studies which supported the research participant's desire for informed, collaborative relationships with health professionals (Dennis, 1987,

Funnel et al,1991). Dennis (1987) found that hospitalized patients consistently desired information in order to effect control. Three types of information based control were identified. Behavioral control over the environment allowed patients to direct activities of daily living. Cognitive control enabled appraisal and interpretation of events and future planning. Decisional control allowed active involvement in treatment and care decisions. While most patients wanted behavioral and cognitive control, more variability was found in the amount of decisional control desired. Dennis (1987) concluded that facilitating the flow of relevant information should be a high priority of nursing care as patients "wanted to have more control over the people and events that impacted their well-being and quality of life while they were in the hospital" (p.154).

The Hospital as a Special Place

Two factors appeared to provide an impetus towards disclosure of illiteracy in the hospital. These factors were the characteristics ascribed to professional care givers, specifically doctors and nurses and the unique characteristics of the hospital as a caring, helping institution.

Characteristics of health care professionals which

appeared to diminish the perceived risk of illiteracy exposure included: knowledgeable and competent; approachable and friendly; kind and caring; understanding and compassionate and most importantly trustworthy and respectful of patient confidentiality. While Jan made a global statement of trust in the role of the nurse, "well the nurse is there to take care of the sick", suggesting that one should just place oneself in their capable hands, others were more cautious based on breaches in expectations of health care professionals experienced in the past. Susan noted that it was easier to share her illiteracy in the hospital "but you can't guarantee what they say is what is. Even sometimes when you go to the doctor the doctor will not keep things private. He will talk to other people who are not looking after you." Luz stated that she would be encouraged to share information "if you look like a friendly person or look like someone I feel comfortable with." Frank required someone who was "very understanding and had the time to spend with you."

The hospital itself was described as special by nature of it's function. Participants saw it as the place where care and teaching were expected and physical vulnerabilities were routinely shared:

Susan: I'm coming to the hospital because I need information about certain things.

Jack: The hospital is a special place because you don't have anybody else unless you have a family come in and read.

Gord: The hospital, it's different, they are there to help you. It's different there...probably because we tell them about private matters.

These two factors, the special characteristics of the hospital and health professionals, have been classified by the researcher as mediating factors. If they were perceived to be in place participants unanimously concurred that it would be to their emotional and physical benefit to share information about their limited reading abilities with doctors and nurses. These factors appeared to moderate or diminish the perceived emotional risks of illiteracy disclosure. In other words, in the hospital the risk of non-disclosure would outweigh the usual risks associated with literacy exposure if the mediating factors associated with the hospital as a special place were perceived to be intact. As well, these characteristics were felt to support the exchange of information required to facilitate participation in decision making.

Support of the "Concept" of Screening

Since response to the concept of screening did not mirror response to the actual screening experience using REALM, it

has been considered separately. Every participant supported the concept of literacy screening in hospitals. While there was agreement that information about reading ability was important to share with doctors and nurses, a dilemma was identified. Several participants stated that they would not have the courage to volunteer this information unless asked directly, and even then some were candid enough to say that they might not be completely truthful in their response. Susan, the least literate participant exemplified this dilemma. While she recognized her reading limitations she clearly stated "doctors and nurses should know....but I wouldn't tell them directly". As well she continued to say that if she was simply asked how well she could read she would probably respond, " Oh, just fine". Getting over the initial disclosure of limited reading ability appeared to be the most difficult hurdle to talking about literacy limitations in the hospital.

While participants were not sure of the most effective way to share literacy information there was agreement that the responsibility for initiating communication about literacy limitations rested with the health care professional, not the patient. Six participants suggested formal methods including reading from word lists or asking patients to read information or consent forms out loud. Two

supported less formal methods such as asking patients to describe their own reading ability. Regardless of the method used to assess literacy ability, participants identified two conditions which would facilitate participation: verbal and non-verbal communication by the health care professional of an awareness and understanding of the sensitive nature of illiteracy and the overt assurance of confidentiality.

Mixed Response to a REALM Experience

Administration of the Rapid Estimate of Literacy in Medicine (REALM) provided an opportunity for the researcher to hear, feel and see the vulnerability most participants experienced when actually exposing their literacy abilities. The portions of text included have been selected to illustrate for the reader the wide range of responses demonstrated.

Despite the trusting relationship and rapport that had been developed with participants as indicated by verbal feedback about the researchers demeanor, the candid and intimate nature of the responses and participants agreement to proceed with the REALM administration, the actual screening process was not easy for most. It should be noted that the researcher took special care to assure a supportive

environment providing positive verbal and physical cues throughout the REALM administration process in an attempt to maintain participant self esteem. In this section emotional, cognitive and physical responses are reported along with participants recommendations for future REALM use as a screening tool to facilitate patient teaching.

Two participants described the REALM experience as positive or neutral. Both appeared relaxed and comfortable throughout. Jan, responded positively, noting, "It was OK....It's good actually to put into hospitals". Carol, who described herself as a "fair" reader was more neutral in her response: "I wouldn't mind doing this in a hospital. It didn't feel like a test. It's sort of like the words you get right, like the small words, it sort of encourages you to go further to get the larger ones."

All others demonstrated some negative response to their REALM experience. Susan was a bit reluctant to proceed with the REALM when she noticed that documentation was occurring on the researcher's form. She was suspicious that this might be a "test" and wondered where the "mark" was going. After clarification, showing her that the form was the same as her own and reassuring her that she could skip this part of the interview or conclude at any time she chose to continue. Susan, appeared to seriously attend to the reading task but

was unable to read most of the REALM words, stating "none of them look familiar." She described her experience as follows: "It made me feel frightened, not frightened, it just made me feel funny."

Jeff read most words correctly, but read very quickly without attempting to figure out the words which were not immediately familiar. He appeared to just want to get it over with. Like Susan, he commented that it felt like a test and noted "I don't do really good when people are watching" remarking that the experience made him feel "uneasy".

While Luz appeared and reported feeling comfortable reading from the word list and stated she felt satisfied with her performance, she commented "if I couldn't have read well at all, like in the past, it would have made me very embarrassed." She also expressed concern with the validity of the REALM. She thought that reading words from a list did not reflect comprehension and went on to say "I would do it, but it doesn't make any sense, at least for me".

Frank demonstrated the strongest negative response to the REALM administration. Several physical signs of discomfort were observed, his face flushed, he started tapping his fingers and after having established rapport and eye contact with the researcher he averted his eyes and it took several minutes to regain eye contact. The possibility

of undermining self confidence and self esteem were all realized during this simulation experience. Frank expressed anger indicating that he believed words were selected in a manner that guaranteed poor readers would feel defeated.

Like, in my opinion, that is defeating the purpose..
..Now you take this person that is either semi-literate or whatever the case is, why put something on there (on the REALM) that you know he is not going to get on with?

I think the whole purpose is to make the person feel comfortable...it's to go into surgery and not be afraid.

But by having him read that, (the REALM) like in my case right there, I was tense and uptight. Now if you would have handed me this form (for example a consent form) and said "is there anything on there you don't understand?" there's no way I would admit it because I'm uptight and feel uncomfortable. I'm not going to let this thing keep going....All that would have done is shut me down.

The REALM experience evidently caused Frank discomfort. The sensitivity of potential illiteracy exposure remained evident even at the stage when Frank considered himself literate. Several minutes of debriefing were required to diffuse this anger and boost this participants self-esteem. Frank also spoke about the conditions he felt were necessary to make this a more acceptable screening process:

You would need someone who was very understanding, who had time to spend with you when this was being done...they couldn't just come in and leave again....If you're not careful with the relationship you're just going to make it more distant.

This response was consistent with that of a pilot participant and appeared to occur when perceived actual performance on the REALM was not congruent with anticipated performance. A 40 year old, female pilot participant in describing responses to unexpected poor performance on the REALM stated: "It would be scary and embarrassing... people might look down on you and say you were not as smart as they thought you were. It would stop people from trying"

Davis et al.(1993) have stated that an advantage of the REALM is the ease with which it can be administered by personnel with little training, "minimal training is required to administer the text; office personnel and research assistants who know the correct pronunciation of words can give the test" (p.395). Frank's response to the REALM experience, along with those of Jeff and Susan, clearly indicated that well developed communication and relationship skills may be required to maintain the self esteem and self confidence of some REALM participants. While this assessment is intended to improve learning outcomes, in some cases it appeared that it may have triggered feelings of decreased self efficacy towards learning, withdrawal, anger and frustration, creating potential barriers to learning.

The literature review indicated that for those with low

literacy skills self assessment of reading ability and actual ability are frequently incongruent (Bristow and Leslie, 1988; Jones, 1992; Hussey and Gilliland, 1989). As well, Bristow and Leslie (1988) noted that adults with limited literacy experience tend to base their understanding of "reading" on decoding skills, such as those used to read words from the REALM list. Based on this information it might be anticipated that the mismatch of perceived reading ability pre and post REALM administration might be a frequent occurrence. While actual REALM interpretation is based on broad ranges of scores, some participants, notably those with higher literacy skills, interpreted any missed word as less than acceptable performance. Only two of the eight participants indicated that they were entirely satisfied with their reading performance on the REALM.

The findings supported the speculation that diminished self esteem and self confidence may be an expected outcome of REALM administration for those who do not perform as well on the reading task as they anticipate.

Despite the negative responses of the majority of participants, six of the eight, stated that they would participate if asked to read from the REALM in a hospital setting. This willingness appeared to be based on a belief that the 'short term pain' of exposure was worth the 'long

term gain' associated with the increased knowledge and independence anticipated as a result of sharing literacy limitations with health care professionals. Two stated they would refuse. Four supported future use of the REALM as a screening tool to assist with planning patient teaching; two were undecided, although they supported some type of screening; and two stated they would not recommend the REALM for use in hospital settings, even though they supported literacy screening in principle.

Summary

In summary, the interviews and simulation experiences which provided the data for the study have provided insight into an aspect of the complex, life experiences of adults with low literacy skills. The data collected were rich, candid and thoughtful. Participants demonstrated their responses through the sharing of thoughts, feelings and actions.

Analysis uncovered several factors which influenced the responses of participants to literacy screening. Perceived risks of both illiteracy exposure generally and non-disclosure during hospitalization were described by participants. The relationship between these opposing forces

was evident in the interviews. The hospital was portrayed as a special institution, based on characteristics ascribed to the environment and health care professionals, especially doctors and nurses. These characteristics may be referred to as mediating factors due to their apparent moderating influence on perceived risks of illiteracy exposure.

The data indicated a positive response to the concept of hospital literacy screening. All participants supported the need for health professionals to initiate activities aimed at exposing literacy limitations. This general support did not translate into an equally favorable reaction to the actual REALM experience. A set of participant specific personal and historic factors appeared to have influenced response to REALM. These included the level of congruence between pre and post REALM self assessed reading abilities and perceptions of the REALM as a test. Not reading as well as expected or viewing the REALM as a test appeared to foster negative responses. As well, the degree of confidence in the integrity of the mediating factors based on past experience in the hospital or with health care professionals influenced the reactions to screening. Finally, the perceived degree of social stigma or social normalcy associated with low literacy and past experience exposing literacy may have influenced the actual response to the

screening experience.

These findings are consistent with the comments of literacy assessment experts cited in the literature review which indicated that adults would not readily accept literacy assessment interventions which represented high emotional or social risk or looked like tests (Finlay and Harrison, 1992; Peers, 1993). Further, these experts suggested that testing which threatens self esteem or creates feelings of anxiety or anger may negatively influence participants performance and hence the validity of results.

CHAPTER 5

CONCEPTUALIZATION AND MODEL BUILDING

The building of substantive theory or conceptualizations of the structure and process related to a phenomenon and comparing it to existing theory is a legitimate and desirable outcome of case study research (Eisenhardt, 1989; Tesch, 1991; Yin, 1984). This approach has been incorporated into this study. While the findings and data analysis were reported in the previous chapter the results will be further interpreted through the presentation of a conceptual model representing the response of low literate adults to literacy screening during hospitalization.

Upon completion of this conceptualization a review of the patient teaching and adult education literature was undertaken to ascertain if well substantiated theories existed which were congruent with the model developed in this study, hence providing a method of triangulation which enhanced the trustworthiness of the findings. While several theories in the domains of social psychology, adult education and health promotion were found in the literature on patient teaching and health promotion, two appeared to be particularly supportive of the model developed in this

research, the Health Belief Model (Becker, 1974; Rosenstock, Strecher and Becker, 1988) and Proficiency Theory (Knox, 1980). The relationship of this new model to these two existing theories will be further explored in this chapter.

A Conceptualization of Response to Screening

A conceptual model demonstrating the factors impacting the response of low literate adults to literacy screening during hospitalization along with hypothesized relationships between these factors was developed from the data and the analysis. This conceptualization indicated that the risks of illiteracy exposure which generally apply to social contexts were balanced against the risks of non-disclosure in a hospital setting. The perceived risks of illiteracy exposure appeared to direct support away from screening, hence these factors were considered to carry a negative or repellent power. On the other hand, the perceived risks of non-disclosure appeared to provide an impetus towards support of hospital literacy screening and were conceptualized as propelling forces. Increased knowledge and ability to control or contribute to care decisions was associated with diminished risks of non-disclosure. Participants anticipated that health professionals'

awareness of patients' reading ability would result in more effective patient teaching.

The strength of these risks seemed to have been interpreted through consideration of mediating factors including the characteristics ascribed to health professionals and to the hospital itself. This accounted for the understanding of the hospital as a 'special' place. The perceived severity of risks normally associated with low literacy exposure in social settings seemed to be moderated in the hospital context. This moderation was based on the expectation of confidentiality and a supportive, caring, relationship with health care professionals in an environment where sharing of vulnerabilities or perceived inadequacies was common and accepted behavior.

While these factors created a positive predisposition to literacy screening during hospitalization, the data suggested that there were individual personal and historic factors which also influenced response to the specific screening tool. Perceiving the screening tool as a test appeared to negatively influence participant response to the REALM as did incongruent pre and post REALM self assessments of reading ability. For example, those who thought of themselves as 'good' readers but felt they had not 'done well' reading the REALM words tended to have more negative

responses to the screening experience than those who viewed themselves as 'poor' readers and saw their ability to read any of the words as a success. As well, the perceived degree of stigmatization associated with low literacy impacted response to screening. Those who had come from families or communities where low literacy was considered common or acceptable responded more positively towards the REALM than individuals who viewed their situation as unique or shameful. Finally, confidence in the integrity of the mediating factors appeared to influence reactions to screening. While participants generally viewed the hospital and health care providers in a very positive way, it was clear that the characteristics ascribed to them represented the "ideal" situation. The quality of past experiences and relationships with doctors and nurses appeared capable of influencing actual response to screening.

A conceptualization of the broad categories of factors influencing the responses of adults with low literacy skills to literacy screening during hospitalization is presented in Figure 1. Examples of each broad category, as identified from the research, are presented in a more detailed summary of the specific factors influencing the research participants response to screening in Figure 2.

Figure 1: A Conceptual Model of the Response of Adults With Low Literacy Skills to Literacy Screening During Hospitalization

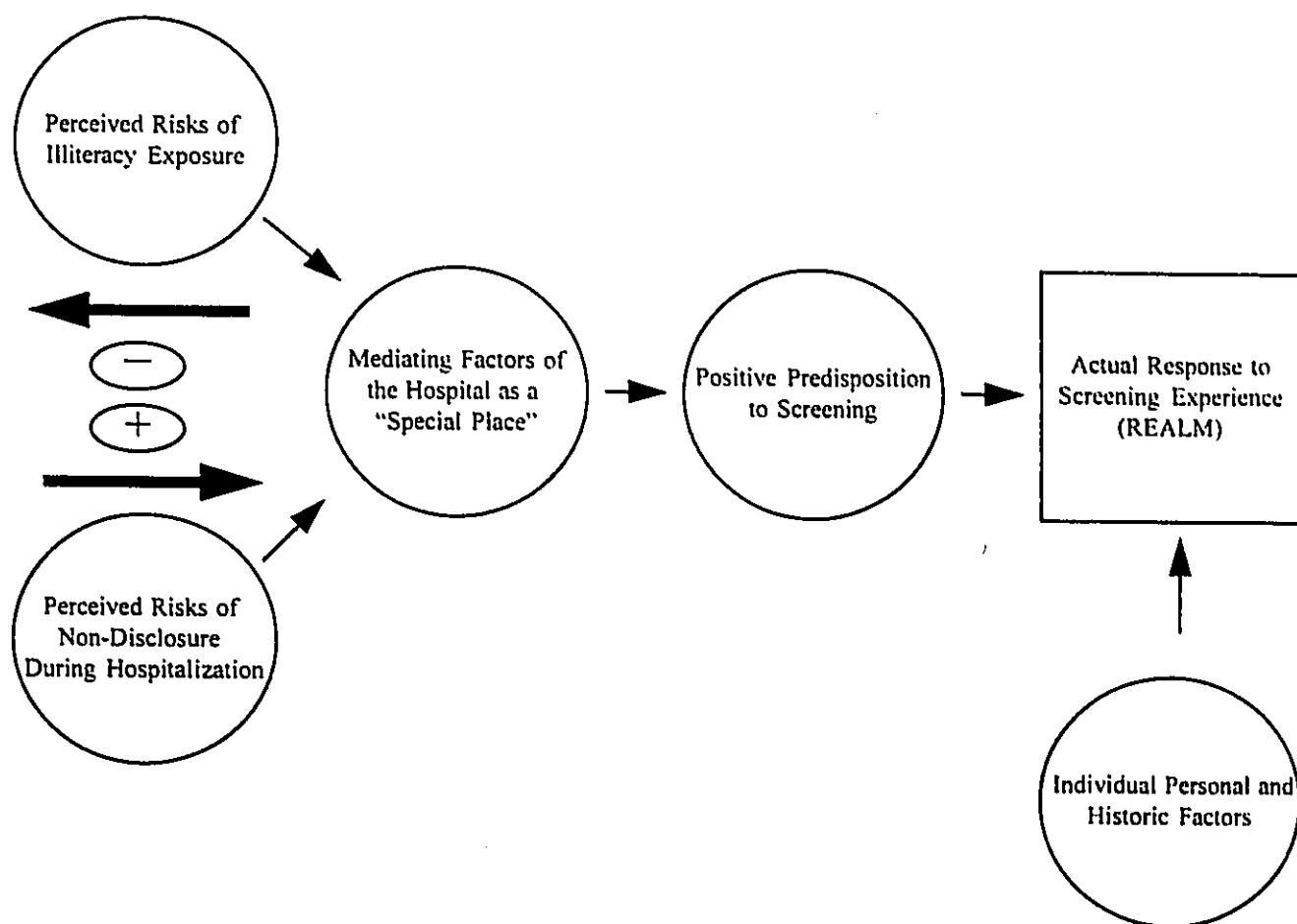
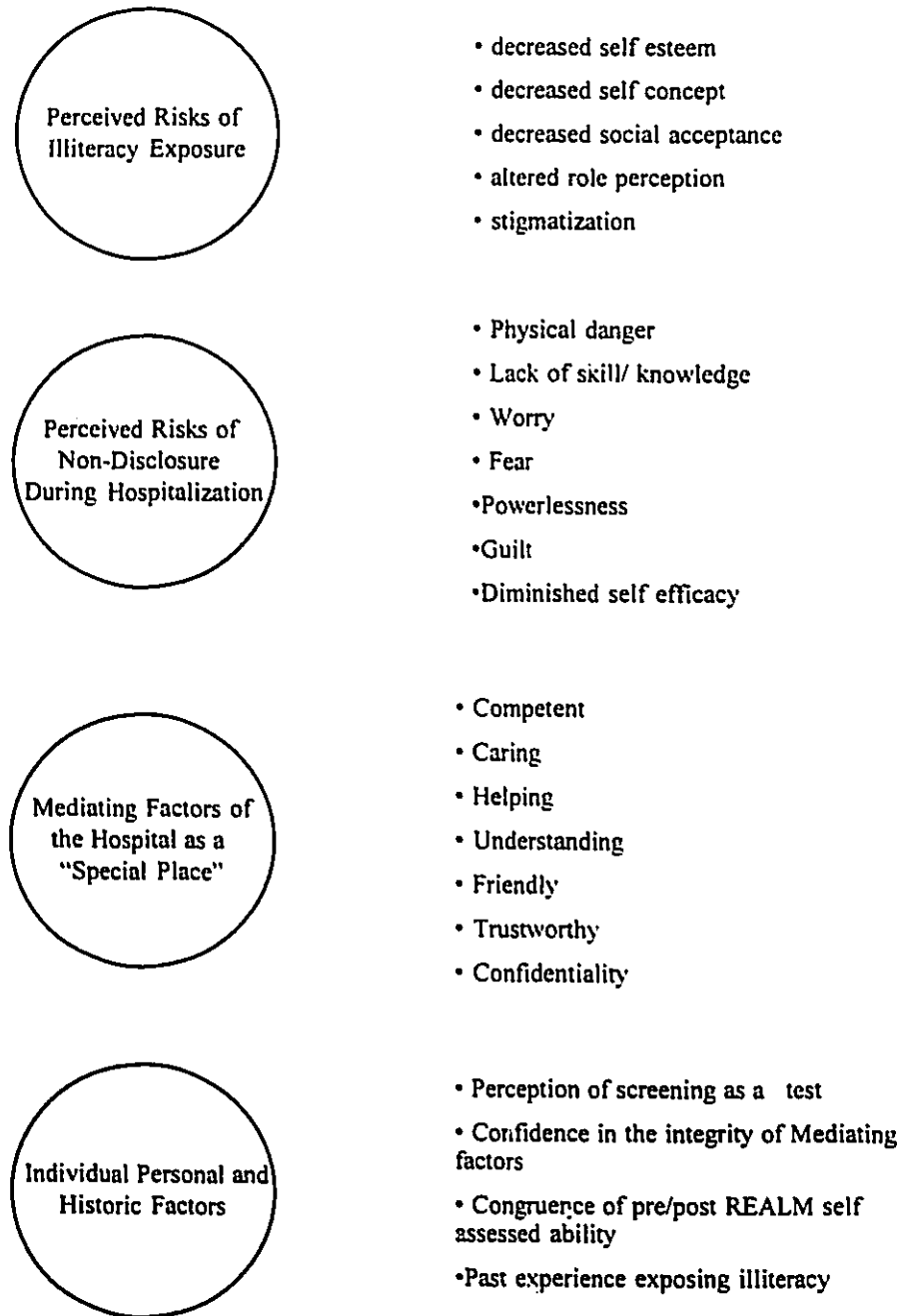


Figure 2: Factors Influencing the Response of Adults With Low Literacy Skills To Literacy Screening During Hospitalization



The Health Belief Model

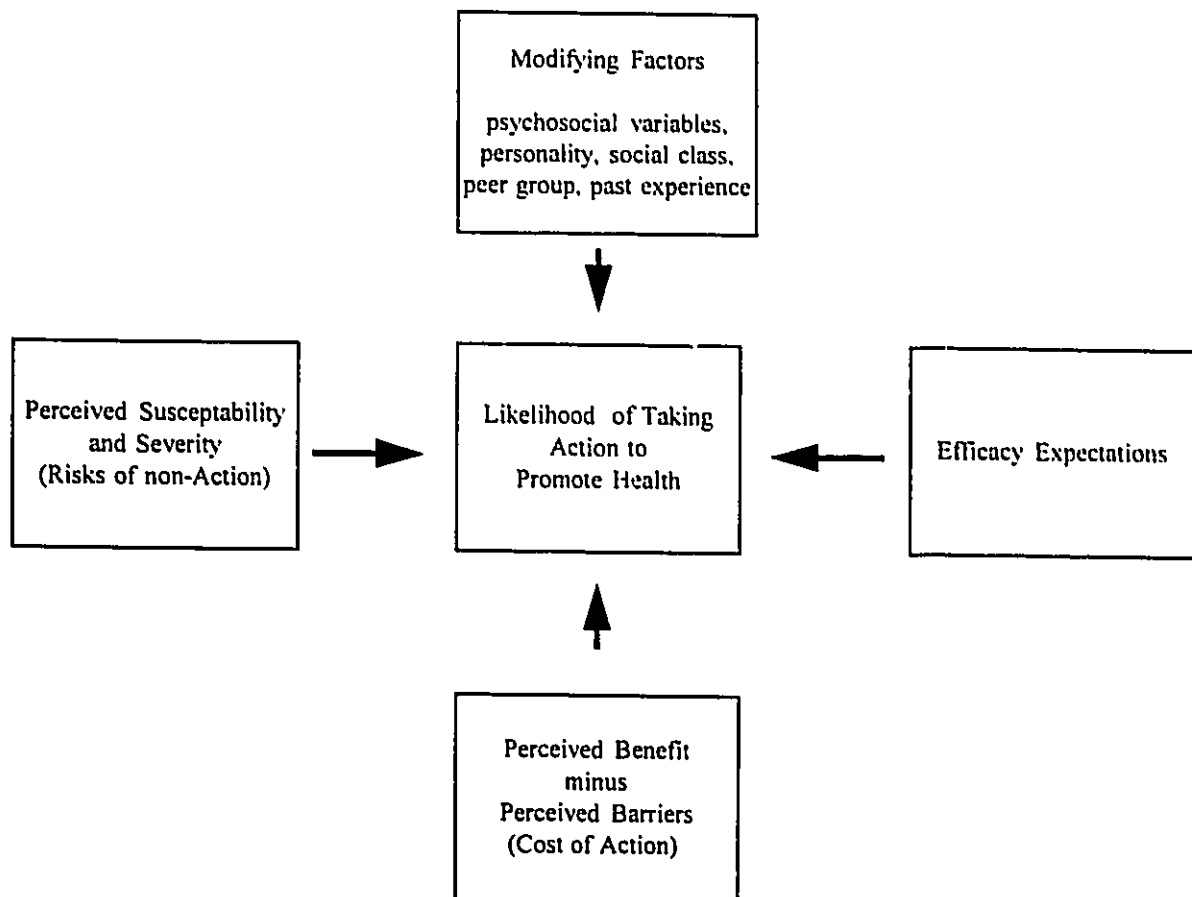
The Health Belief Model has been used for more than two decades in an attempt to describe and explain the decision making process used by individuals in determining health promotion behaviors. Becker (1974) described the model as an "attempt to explain action in a choice situation"(p.9). It is a theory which belongs to a group of learning theories developed around the concept of value expectancy and based on the seminal work of Kurt Lewin. Lewin hypothesized that behavior was dependent upon two major variables; the value placed by the individual on the outcome and the individual's self estimate of the likelihood that a given action would achieve the desired outcome (Becker, 1974). This perspective appeared to fit well with the goal oriented learning of patient teaching. Over the years the Health Belief Model has been tested, refined and altered in attempts to maximize it's explanatory power.

This theoretical explanation of the process for decision making in the context of health and illness was based on the understanding that each individual responds in a unique way based on their current perceptions of risk. In order for an individual to behave in a way that would promote health he must believe that he is susceptible to a

sufficiently severe negative outcome that the anticipated benefit of behaving in a certain way would reduce the severity of the perceived negative outcome. As well, the individual must believe that the perceived costs, for example inconvenience, pain, embarrassment etcetera, do not outweigh the perceived benefits. Finally, the likelihood of taking action at all towards health promotion activities is influenced by the degree of self efficacy the learner attributes to the required activity. High efficacy expectations encourages action, low efficacy expectations discourages it.

The main concepts of the Health Belief Model included: perceived susceptibility and seriousness, or the subjective assessment of the risks of non-action; the perceived benefits of action; the barriers or perceived risks of action including emotional, physical and economic factors and the degree of self efficacy felt towards the activity. Demographic, psychosocial and structural variables were considered to serve as factors which condition or influence the individuals perception of benefits and risks. The components of the Health Belief Model have been presented in Figure 3.

Figure 3: The Health Belief Model



The Health Belief Model adapted from Becker, 1974; Rosenstock, Strecher & Becker, 1988.

This well tested and frequently cited model demonstrated a high level of congruence with the factors contributing to the response to literacy screening found in this study. Perceived risks of illiteracy exposure may be considered as a barrier or cost to action. Perceived risks of non-disclosure of illiteracy is a concept parallel to the Health Belief Model's perceived susceptibility and severity, providing motivation to take health promotion action. This theory also supported the process of risk:benefit analysis that was clearly evident in the study. The consistency of these findings strengthen the credibility of the new model developed as a result of this research.

While the modifying factors in the Health Belief Model were also similar to the individual personal and historic factors of the model developed in this research, there was one area where the new, substantive model, was not congruent with the Health Belief Model. Learning environment was not specifically addressed as an independant factor in this model but for participants in the study, the mediating factors, or perceptions of the hospital as a "special" place, appeared to play a significant role in decisions to risk literacy exposure in order to promote health. It appears from these findings, that the environmental context or milieu of the learning experience has the potential to

considerably influence behaviors for adults with low literacy skills. This finding may be related to a recognition by these individuals of the social stigma associated with illiteracy and the high estimation of the cost of exposure in unprotected social situations.

The Health Belief Model has been used in a variety of health care settings, however it was originally developed to explain health promotion and illness prevention behaviors in the community. Perhaps further investigation is required to reconsider the impact of learning environments, such as the hospital, on health promotion activities, especially for vulnerable populations such as adults with low literacy skills.

Proficiency Theory

While no references to Knox's Proficiency theory were found in the health promotion or patient teaching literature reviewed, it has been recommended as a theory of adult learning worthy of further consideration (Merriam,1993). It includes conceptualizations which make its application to patient teaching attractive, especially if one supports the assumption that adults possess unique characteristics as learners.

Knox's Proficiency theory focuses on adults engaged in purposeful and systematic learning activities such as patient teaching, and on the process of helping adults learn. It views adult learning as a transactional encounter and therefore describes learning from both the learner's and teacher's perspective. It is the learner's perspective which will be further considered here.

Proficiency is defined as "the capability to perform satisfactorily if given the opportunity" (Knox, 1986, p. 16). The constituents of performance include knowledge, skill and attitudes. Knox made the assumption that adults desire and value proficiencies that maintain their psychological and physical integrity and autonomy. This assumption appeared to be well supported in the study with all participants indicating a desire for appropriate patient teaching in order that they might become more capable and less dependent participants in care decisions and practice. In other words, taking steps to minimize proficiency gaps may be viewed as a way to diminish perceived risks of non-disclosure of illiteracy.

The awareness of discrepancies between actual or perceived proficiency and desired proficiency creates motivation to learn. Knox suggested that this awareness of proficiency gaps is frequently precipitated by significant

life changes such as job loss, change in family composition and roles or illness, further supporting application of this theory to health care contexts.

Whether this motivation is sufficient to cause an individual to engage in learning is dependent on many factors. According to Knox (1980), the probability of performance is influenced by: a perceived proficiency gap; habit and experience; facilitating conditions and individual behavior intentions. Facilitating conditions include the situational influences of social roles, norms and perceived expectations as well as the personal influences of self concept and self confidence in existing knowledge and skill. Behavior intentions are described as being closely linked to the value of the perceived consequences of performance. For most adults "major learning efforts are discouraged by low anticipated benefits in exchange for high costs and risks" (Knox, 1980 p, 385). Knox hypothesized that learning is motivated by the identification of problems to be solved or discrepancies between current and desired proficiencies.

The concepts of habit and previous experience are consistent with the concept of perceived risk of literacy exposure. Individual behavior intention reflects the perceived value of anticipated consequences of action and as such is comparable to the notion of perceived risks of

non-disclosure. Facilitating conditions, both situational and personal, may be compared to perceived mediating factors and personal historic factors described by the research participants. Knox considers contextual aspects of the learning environment or educational climate under this broader category of facilitating conditions. While situational factors are recognized in Proficiency theory, it does not single out the learning environment as a major, independent motivational factor encouraging learning.

Summary

Comparing the factors which influence decision making in the new response to screening model with the Health Belief Model and Proficiency theory has demonstrated many similarities in concepts and relationships. Perceived risks of illiteracy exposure described by participants were similar to the Health Belief Model's perceived barriers and costs of action and Knox's concepts of habit and previous experience. Perceived risks of non-disclosure during hospitalization paralleled the Health Belief Model's perceived susceptibility and severity and Knox's individual behavior intention resulting from the awareness of proficiency gaps. All models described a process of

risk:benefit analysis. Proficiency theory and the Health Belief Model described facilitating or modifying factors such as personality, social class, peer group, past experience, social expectations and age which were felt to influence the interpretation of perceived risks and benefits. As well, these factors may contribute independently to motivating individuals to learn. These factors are similar to the mediating and individual personal and historic factors found to influence participants response in this study.

The differences appear to be mainly in the strength attributed to the motivational factors. The Health Belief Model described the outcomes of the risk:benefit analysis and perceived seriousness and susceptibility as the most influential motivating factors. Knox's Proficiency theory focused on discrepancies and desires for proficiency within a social context. Both of these motivational factors were supported by the findings of this study. The similarities of the emergent conceptual model with existing theories from the domains of health promotion and adult education lend support to the credibility of the research.

As well, this comparison has demonstrated the applicability of Proficiency theory to the phenomenon of patient teaching. Clearly, further investigation will be

needed in order to clarify the role of proficiency attainment in motivating health promotion activities, however this research suggests that this theory may provide a suitable framework for future consideration of patient teaching questions.

The apparent strength of the impact of the contextual or environmental characteristics of the learning setting, such as viewing the hospital as a special place, was not fully accounted for by either of the compared theories. The unique characteristics and role of the hospital as a learning environment, and the impact of this environment on learning behaviors of adults with low literacy skills are important but under developed concepts which have emerged from this research.

CHAPTER 6

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Chapter six is the final chapter in the thesis. It includes a summary of the study and results. The reader will also find reflections on the implications of the study to educational theorizing and patient teaching. The concluding section will offer some suggestions for future research.

Review of the Study

There is clear evidence of a shift in health care philosophies and practice towards an expectation of increased individual responsibility for personal health care decision making and participation in health promotion activities. The patient teaching and health promotion literature has indicated that this expanded role depends on consumers who are knowledgeable and skilled. This trend will have a significant impact on more than 30% of Canadians who have low literacy skills. They are a vulnerable population on two counts. Not only do they experience poorer health than their literate counterparts, they are unable to fully

benefit from the difficult print materials health care providers often use for gathering and disseminating health information.

This awareness has lead to recommendations that literacy screening tools, such as the Rapid Estimate of Reading in Medicine (REALM), be employed in health care settings as part of the needs assessment for planning patient teaching. While knowledge of reading ability may facilitate selection of appropriate educational strategies leading to enhanced efficiency and effectiveness of educator effort, the response of the learner to such screening has not been investigated.

The purpose of this study was to gain an understanding of the response of individuals with low literacy skills to screening reading ability for health teaching in general, and specifically to the use of the REALM tool for this purpose.

This previously unstudied phenomenon was investigated using a qualitative, case study design. Eight English speaking adults with low literacy skills participated in the research. Data were collected through semi-structured interviews which included a literacy screening simulation experience using the REALM and participant observation.

Data were analyzed using a constant comparison

technique. Within and across case analysis was undertaken in a sequential and iterative way to develop categories and themes. As is desirable in case study research this method of analysis facilitated the building of a conceptual representation of the factors influencing participant response to literacy screening. This model has been presented in chapter five.

Conclusions

The findings of the study indicated that several factors appeared to influence the response of participants to literacy screening for the purpose of facilitating the planning and delivery of appropriate patient teaching in the hospital setting. These factors included the perceived risks of literacy exposure, the perceived risks of non-disclosure, the attribution of characteristics to the hospital that make it a "special" place and the perceived strength of these characteristics.

The perceived risks of illiteracy exposure were described as decreased self esteem and self concept, social ostracism, increased dependence, altered role perception and stigmatization. These factors were found to be balanced by an opposite set of compelling forces, the perceived risks of

non-disclosure during hospitalization. The risks of non-disclosure included possible physical danger and diminished health, worry, fear, powerlessness, guilt and diminished self-efficacy. Participants felt that the characteristics of trust, competence, caring and confidentiality which they attributed to the hospital and health care workers acted as mediating factors which allowed the risks of non-disclosure to outweigh the risks of disclosure. This risk:benefit analysis appeared to result in a positive predisposition to literacy screening within the hospital setting.

In all cases, even though participants anticipated a degree of emotional discomfort with the screening process, they supported the concept of screening in the hospital. There was not, however, unanimous support of the use of the REALM tool for this purpose. Four factors, associated with the learners' past experience, appeared to influence the response to this specific screening approach. These factors included perception of the screening instrument as a test; the degree of confidence in the integrity of the mediating factors; the congruence of pre and post screening self assessment of reading ability; and finally the learner's perception of stigma associated with illiteracy. In other words, the REALM experience was responded to more negatively

by those participants who viewed the instrument as a test, had previous hospital experiences where confidentiality had not been maintained and by those who had an inaccurately high perception of their actual reading ability which was challenged by the screening process. Those participants who came from families or communities where illiteracy was more common appeared to have less intense negative responses to screening.

Implications for Practice

Despite the small sample, the consistency and strength of the responses by participants along with the good "fit" of these responses to the literacy literature and existing theories of learning supports the consideration of these findings by health care professionals contemplating the use of literacy screening tools in practice.

As noted at the beginning of the study a screening tool, such as the REALM, which is quick to administer, easy to interpret, directs the user to appropriate teaching strategies and is accepted by patients would be extremely beneficial for hospital use. It could lead to enhanced efficiency and effectiveness of educator effort and improved patient learning outcomes.

The research suggested that adults with limited reading skills support the concept of literacy screening. They agreed that doctors and nurses working in hospitals should be aware of patients' reading abilities and should initiate discussions aimed at identifying literacy limitations. It cannot, however, be assumed that this support automatically applies to all screening methods, including the REALM.

Indications were seen that REALM administration is not an entirely benign procedure. Some participants demonstrated diminished self esteem and self efficacy as a result of the simulation experience. Based on the findings of the study and in light of the dearth of other research addressing the issue of learner response to literacy screening for patient teaching, the practitioner may be advised to proceed with caution. Those who intend to use the REALM or other instruments for literacy screening purposes may wish to consider the following conditions. Privacy and confidentiality must be assured and communicated to the patient. Signs of diminished self esteem should be monitored closely, including observation for changes in body language, tone of voice and verbalization of diminished self concept. Supportive interventions, both through verbal and non-verbal means may be required. Negative responses may be anticipated in individuals who experience unexpected difficulty reading

from the REALM. Based on the frequency and intensity of emotional responses observed in this research, it is strongly recommended that literacy screening be undertaken only by those who have training in communication skills and building therapeutic relationships. As well, health care professionals would be advised to clearly apprise patients of the intended purpose of screening and follow through on their responsibility to provide appropriate learning opportunities. Finally, the REALM should be administered by individuals who have received training related to the potential risks of illiteracy exposure and the special learning needs of those with low literacy skills.

The researcher is not advocating a particular approach to literacy assessment. Clearly, some methods of direct assessment carry potential emotional risks for patients and informal methods, while less reliable, may be preferred. Whichever approach is used, the practitioner should attend to the provision and maintenance of the kinds of relationships and environment that contribute to the image of the hospital as a "special" place.

Responsibility for patient teaching must not be abdicated in busy hospital settings when time is at a premium. Distributing information through printed materials does not replace interactive teaching and learning.

Reevaluating the trend towards reliance on written materials for gathering and disseminating information might be well considered. All individuals, especially those patients with low literacy skills, may benefit from the development of clear, plain language printed resources and audio-visual presentations to augment instruction. Presenting patients with a wide range of learning options and allowing them to select that which best suits their learning style may improve the efficacy of teaching efforts without the need for literacy screening.

The large number of adult Canadians with limited reading skills is a reality not likely to change soon. This information should make the development of effective learning resources a priority for health care institutions. Including those with limited reading skills and members of literacy advocacy groups in the developmental process can only strengthen the utility of these efforts. Literate professionals cannot presume to understand the needs of those who do not read.

Throughout this research, from the literature review and discussions with colleagues to the interviews with participants, it became increasingly clear that health care professionals are not fully aware of the incidence of low literacy nor it's impact on the daily life and health of

individuals. Adding discussions of such topics to nursing and medical curriculums may enhance understanding of these issues, promote patient advocacy and improve the health teaching provided for adults who do not read well.

Suggestions for Future Research

As adult illiteracy is an under-studied phenomenon the suggestions for future research generated from this study are many. Further investigation of the explanatory ability of adult learning theories, to adults with low literacy skills, would help to clarify whether transfer of previous findings to this population is justified. The application of Proficiency theory to patient teaching situations appears to be worthy of further consideration as many of it's components were supported by the findings of the research. Continued use of qualitative methodology will improve the understanding of this population's perspective on patient teaching issues.

Replication of this study in other settings or sampling individuals not enrolled in literacy classes would offer a welcome challenge to the model. Further clarification of the concept of the hospital as a special place and the impact of context on learning, especially for adults with literacy

limitations is required. Developing tools to measure self esteem and self efficacy that have been validated for use with adults with low literacy skills would allow further investigation of the length and strength of the negative response to literacy screening allowing a better understanding of the impact of screening on the learning process. As well, further study of the combinations and relative impact of factors identified as contributing to the response to literacy screening would provide valuable information to refine the model.

Once the impact of screening is better understood, replication of this study with a hospitalized sample and investigation of health care workers response to assessing patients' literacy abilities would further elucidate the phenomenon of literacy screening as a means of improving patient teaching and learning for adults with low literacy skills.

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Appendix A

RAPID ESTIMATE OF ADULT LITERACY IN MEDICINE (REALM)[®]

Terry Davis, PhD • Michael Crouch, MD • Sandy Long, PhD

Patient Name/Subject # _____ Date of Birth _____ Reading Level _____
 Grade Completed _____
 Date _____ Clinic _____ Examiner _____

List 1	List 2	List 3
fat _____	fatigue _____	allergic _____
flu _____	pelvic _____	menstrual _____
pill _____	jaundice _____	testicle _____
dose _____	infection _____	colitis _____
eye _____	exercise _____	emergency _____
stress _____	behavior _____	medication _____
smear _____	prescription _____	occupation _____
nerves _____	notify _____	sexually _____
germs _____	gallbladder _____	alcoholism _____
meals _____	calories _____	irritation _____
disease _____	depression _____	constipation _____
cancer _____	miscarriage _____	gonorrhea _____
caffeine _____	pregnancy _____	inflammatory _____
attack _____	arthritis _____	diabetes _____
kidney _____	nutrition _____	hepatitis _____
hormones _____	menopause _____	antibiotics _____
herpes _____	appendix _____	diagnosis _____
seizure _____	abnormal _____	potassium _____
bowel _____	syphilis _____	anemia _____
asthma _____	hemorrhoids _____	obesity _____
rectal _____	nausea _____	osteoporosis _____
incest _____	directed _____	impetigo _____

SCORE	
List 1	_____
List 2	_____
List 3	_____
Raw Score	_____

RAPID ESTIMATE OF ADULT LITERACY IN MEDICINE

The Rapid Estimate of Adult Literacy in Medicine (REALM) is a screening instrument to assess an adult patient's ability to read common medical words and lay terms for body parts and illnesses. It is designed to assist medical professionals in estimating a patient's literacy level so that the appropriate level of patient education materials or oral instructions may be used. The test takes 2 to 3 minutes to administer and score. The REALM has been correlated with other standardized tests.

Correlation of REALM with SORT, PIAT-R, and WRAT-R			
	PIAT-R Recognition	SORT	WRAT-R
Correlation Coefficient	.97	.96	.88
P Value	$p < .0001$	$p < .0001$	$p < .0001$

Reliability Studies	
Test-Retest	Inter-Rater
(n = 100)	(n = 20)
.99	.99

DIRECTIONS:

1. Give the patient a laminated copy of the REALM and score answers on an unlaminated copy that is attached to a clipboard. Hold the clipboard at an angle so that the patient is not distracted by your scoring procedure. Say:
"I want to hear you read as many words as you can from this list. Begin with the first word on List 1 and read aloud. When you come to a word you cannot read, do the best you can or say 'blank' and go on to the next word."
2. If the patient takes more than five seconds on a word, say "blank" and point to the next word, if necessary, to move the patient along. If the patient begins to miss every word, have him/her pronounce only known words.
3. Count as an error any word not attempted or mispronounced. Score by marking a plus (+) after each correct word, a check (✓) after each mispronounced word, and a minus (-) after words not attempted. Count as correct any self-corrected word.
4. Count the number of correct words for each list and record the numbers in the "SCORE" box. Total the numbers and match the total score with its grade equivalent in the table below.

GRADE EQUIVALENT	
Raw Score	Grade Range
0-18	3rd Grade and Below Will not be able to read most low literacy materials; will need repeated oral instructions, materials composed primarily of illustrations, or audio or video tapes.
19-44	4th to 6th Grade Will need low literacy materials; may not be able to read prescription labels.
45-60	7th to 8th Grade Will struggle with most patient education materials; will not be offended by low literacy materials.
61-66	High School Will be able to read most patient education materials.

Appendix B

Appendix C

Guideline for Interview Questions

Sometimes, in the hospital, people need to learn important things so they can make decisions about their care or look after themselves or their children when they get home. Often people are given this important information in writing. (You might need to learn about taking care of a new baby, or about medicines or special diets or even about danger signs to watch for so you don't get sick again. You might have to make decisions about having treatments and sign consent forms or fill out your menu). I would like to find out how people who have a hard time reading feel about sharing this information with doctors and nurses in the hospital.

Demographic Information: (May save until end of interview)

1 Age: 18-29____ 30-39____ 40-49____ 50-59____ 60+____

Gender: Male____Female____

2. Are you a student in literacy program?

Now: No____Yes:____Where?____ In Past: No____Yes____When?____

3. How would you describe your ability to read now?

4. Have you or your child ever been patients in a hospital?(Eg. When you had a baby, if your child was admitted or treated in emergency, for surgery or tests etc) When? How would you describe your ability to read at that time?

Attitudes/feelings about literacy exposure:

5. In your opinion, how, if at all, did your reading effect your hospital stay? Can you tell me about this?

6. How do you think you would feel if you had to learn something important and your nurse gave you information that was too hard for you to read and understand? Has this ever happened to you? How did you find out the information you needed?

7. In the hospital did you ever pretend to understand something that was written even if you didn't? (If yes, Why?)
8. Do you think you would be more likely to tell people about your reading difficulties in the hospital than other places? Why?

Feelings/attitudes about hospital screening:

9. Do you think doctors and nurses need to know how well patients can read? If no why not? If yes, how do you think they should find out this information?
10. How do you feel about letting your doctor or nurse know you have a hard time reading?

PRE-REALM

12. Do you think you read well enough to understand written instructions about treatment or medication you might need to take if you were sick?
13. Right now, how confident (or sure) do you feel about being able to learn, by reading, about the side effects of a new drug your doctor might give you?

REALM Administration:

14. Some people say this reading form should be used in the hospital to help your nurse or doctor plan the best way to teach you. I would like you to try to read these words and then we will talk about this experience. (administer REALM according to directions)

REALM response:

15. How did doing this reading make you feel?
16. How confident do you feel, right now, about being able to learn, by

reading, about a new drug your doctor might give you? Do you feel differently about your ability now than you did before you did this reading?

17. If you were asked to do this reading in the hospital do you think you would do it?

18. Would you read for your nurse or doctor even if you really didn't want to? If yes, why?

19. Do you think this form should be used in the hospital to help plan patient teaching? Why or why not? How do you think it can be best used?

Appendix D

Literacy Research Study

CONSENT FORM

I (please print name)_____ have read the
letter of information and agree to take part in this study.
I have been given the chance to ask questions.

Signed_____(Participant)

Signed_____(Researcher)

Date_____

