# RISK COMPREHENSION OF ONLINE COLORECTAL CANCER INFORMATION: AN ASSESSMENT OF HEALTH NUMERACY

by Lorie Donelle

A thesis
presented to the University of Waterloo
in the fulfillment of the
thesis requirement for the degree of
Doctor of Philosophy
in
Health Studies and Gerontology

Waterloo, Ontario, Canada, 2007

© Lorie Donelle, 2007

# Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Lorie Donelle

## **Abstract**

Introduction: Colorectal cancer is the third leading cause of cancer among Canadians and the second leading cause of cancer deaths. In this age of chronic disease and shared decision-making, individuals are encouraged and expected to contribute to decisions about healthcare. Increasingly, Canadians rely on the Internet as an access point to healthcare information. Health literacy, particularly adequate numeracy skill, occupies a central role within cancer care communication and is requisite to meaningful participation in risk-based decision-making. Despite this, numeracy has attracted little research attention. Consequently, the primary objective of this study was to investigate the influence of health numeracy skills, health prose literacy, math anxiety, attained education, and context of information on participant ability to comprehend Internet based colorectal cancer risk information.

Method: Demographic details were collected on 140 older Canadian volunteers. Health literacy (prose and numeracy), and math anxiety scores were also obtained. Prose literacy was measured by the STOFHLA whereas numeracy was assessed using three instruments (general context numeracy, health context numeracy, and the STOFHLA). Math anxiety was measured by the Abbreviated Math Anxiety Scale (AMAS). The assessment of participant risk comprehension was based on two web pages of colorectal cancer information. The two web pages were chosen from the Canadian Cancer Society; one represented 'common' information and the other represented 'uncommon' information. Multiple regression analysis was employed to determine the influence of explanatory variables on participant risk comprehension.

**Results:** The majority of older adults (91%) in this convenience sample had 'adequate' functional health literacy as measured by the STOFHLA. Participants revealed wide variation of numeric competency with high STOFHLA numeracy scores, moderate

levels of health context numeracy and math anxiety, but poorer general context numeracy skill. The mean score for participant comprehension of colorectal cancer risk was 16.8/22. There was a significant difference between risk comprehension scores on 'common' (9.14/11) and 'uncommon' (7.64/11) web-based cancer information with better comprehension of the 'common' information. Approximately 60% of the variation in participant risk comprehension scores was explained by the prose health literacy, general context numeracy, health context numeracy, STOFHLA numeracy, math anxiety, and level of education. Additional regression modeling highlighted the significance of health context numeracy skill for both 'common' and 'uncommon' cancer information and the need for the combined skills of prose health literacy and numeracy for comprehension of 'uncommon' web-based cancer risk information.

Conclusion: Adequate health numeracy skill is a necessary component for understanding online cancer information. A spectrum of health numeracy skill ranging from basic to more advanced proficiency is needed for comprehension of cancer risk information. For comprehension of less familiar subject matter, 'content' knowledge or enhanced prose health literacy skill, jointly with health numeracy skill, is required. This research underscores the need for continued investigation of the role of health literacy (prose and numeric) in the comprehension of online cancer information among diverse groups of healthcare consumers. These findings highlight the need for continued research directed at concept clarification and concept modeling of prose health literacy and numeracy. Research focusing on the development of a comprehensive health numeracy assessment instrument is recommended. Also, these findings have important implications for health educators in designing online cancer information. Cancer information specialists and web designers are encouraged to exploit the versatility of the Internet in order to construct web-based cancer information to accommodate the continuum of health literacy/numeracy skill that currently exists.

## **ACKNOWLEDGEMENTS**

This achievement represents the knowledge, skill, support, and kindness of so many others. I have been so fortunate in having Jose Arocha and Laurie Hoffman-Goetz as supervisors. Jose, I am so grateful for the thoughtfulness, academic expertise, and the encouragement you have offered throughout my time at Waterloo. You welcomed me to the University of Waterloo and into the health informatics community and have provided incredible opportunities for learning. Your encouragement and support has been present since our first introduction and you have continued to support me in pursuing my academic / professional goals. I appreciate your professionalism and your friendship.

Laurie, I admire your passion for excellence and learning. You have made an incredible contribution to the academic world and continue to do so. You model discipline, hard work, and academic and professional integrity. I feel so fortunate for and have benefited from your generosity, your leadership, and support. I am grateful for the learning opportunities you provided for me and for the chance to work together with you. Your guidance has been invaluable and instrumental to my academic and career achievements. Above all, I value your kindness, thoughtfulness, and friendship. I look forward to our continued collaborations.

Thank you to all of the staff and faculty within Health Studies and Gerontology for making my time here so memorable. I especially want to thank Steve Brown, Linda Jessup, and Sharon Campbell for generously offering their time and expertise as thesis committee members. Thank-you to Dr. Irving Rootman for your interest in this work and for your willingness to contribute to my doctoral experience as an external committee member. My appreciation extends to the 140 participants for their valued contributions.

My enjoyment within the doctoral program is largely the 'fault' of the many incredibly talented and intelligent colleagues I have had the good fortune to meet. I especially want to thank Daniela Friedman, Vivienne Vance, Sarah Viehbeck, and Robin Blanchard for their constant support, their much appreciated sense of humour and sense teamwork throughout my time at Waterloo. I truly admire the unassuming attitude you present regarding your ambition, skill, and intelligence. I am so proud to know you and look forward to hearing about your continued success.

It is largely because of the support from friends and family that I have been able to pursue my doctoral studies. The weekend running group has on more than one occasion provided me with a balanced perspective and renewed energy. I especially want to thank Nancy Gateman, Akeela Rabley, and Val Stinson and for their friendship, and encouragement. Nancy thanks for the many miles we've logged on the trail. To Dave, Linda, McKenzie, Lesley, John, Garret and Courtney – thanks for your encouragement - I have the best family. Thank you so much to my two sons, Scott and Matt for your support, patience, and love. I am so proud of you both.

I would not be sane without the love, support and understanding from my Mom. Mom – you are amazing! With your help I was able to focus on school because I knew that everything was so well looked after at home. I attribute my success to you.

To my husband, Rich – I share this accomplishment. You are so encouraging and supportive. I always know that I have your understanding, patience, sense of humour and love to get through anything. You model optimism, integrity, honesty, and hard work. I think you are an incredible father, friend, and husband.

# **Table of Contents**

List of Figures	X
List of Tables	xi
Introduction p. 1	
Chapter 1: Literature Review	p. 4
1.1 Introduction	p. 4
1.2 General Literacy	p. 4
1.2.1Prose Literacy	p. 6
1.2.2 Numeracy	p. 7
1.3 Health Literacy	p. 9
1.3.1 Numeracy and Health	p. 15
1.3.2 Prose Literacy and Numeracy in the Elderly	p. 20
1.4 Prose and Numeric Literacy and Education	p. 21
1.4.1 Education and Numeracy in Healthcare	p. 24
1.5 Numeracy and Skill Utilization	p. 25
1.6 Numeracy and Context of Information	p. 26
1.7 Measurement of Health Literacy and Numeracy	p. 27
1.8 Framework for Risk Comprehension	p. 34
1.9 Summary of the Literature	p. 38
1.9.1 Study Components and Rationale	p. 40
Chapter 2	p. 43
2.1 Abstract	p. 43
2.2 Research Objectives	p. 44
2.3 Hypotheses	p. 44
2.4 Introduction	p. 46
2.5 Methods	p. 48
2.5.1 Recruitment of Participants	p. 48
2.5.2 Functional Health Literacy	p. 50
2.5.3 Three Item General Numeracy Assessment	p. 50
2.5.4 Eight Item Health Numeracy Assessment	p. 51
2.5.5.The Abbreviated Math Anxiety Scale (AMAS)	p. 51
2.5.6 Statistical Analysis	p. 52
2.6 Results	p. 53
2.6.1 Literacy and Numeracy Profiles of Participants	p. 55
2.6.2 Regression Modeling of General Numeracy and Health	
Numeracy	p. 60
2.6.3 Moderated Effect of Education by Math Anxiety	<b>p.</b> 00
on Health Numeracy Skill	p. 62
2.7 Discussion	p. 62
2.7.1 Numeracy Measured by the Three Item General	p .00
Context Scale	p. 65
2.7.2 Numeracy Measured by the Eight Item Health	p. 00
Context Scale	p. 66
2.8 Conclusion and Implications for Practice	p. 60 p. 67
2.0 Conclusion and Implications for Fractice	P. 07
<b>Chapter 3: Risk Comprehension and Online Colorectal Cancer Informatio</b>	n:
Impact of Health Numeracy	p. 69
• · · · · · · · · · · · · · · · · · · ·	

3.1 Abs	tract	p. 69
3.2 Rese	earch Objectives	p. 70
3.3 Hyp	· · · · · · · · · · · · · · · · · · ·	p. 70
3.4 Intr	oduction	p. 71
3.5 Met	hods	p. 74
	3.5.1 Participants and Procedures	p. 74
	3.5.2 Statistical Analysis	p. 77
3.6 Resu	ults	p. 78
	3.6.1.Demographic Characteristics of Participants	p. 78
	3.6.2.Literacy and Numeracy Profiles of Participants	p. 78
	3.6.3 Participant Subjective Risk Appraisal	p. 80
	3.6.4 Risk Comprehension	p. 81
	3.6.4.1.Regression Modeling of Risk Comprehension	p. 81
<b>3.7.Disc</b>		p. 84
3.8.Con	clusion and Implications for Practice	p. 87
Chapter	r 4: General Discussion and Implications for	
Practice	e and Research	p. 89
4.1 Ove	rall Findings	<b>p.</b> 89
<b>4.2 Pros</b>	se Health Literacy / Numeracy Skill	p. 90
	4.2.1 Health Numeracy	p. 94
	4.2.2 Assessment of Health Numeracy	p. 99
	4.2.3 Risk Comprehension and Numeracy	p.100
4.3 Stud	ly Limitations	p.106
4.4 Dire	ections for Future Research	p.111
<b>4.5</b> Con	clusions	p.114
Appendix A: Tl	hree Item and Expanded Eight Item Numeracy	
	Assessment	p.116
Appendix B: T	The Newest Vital Sign Assessment	p.117
	CCS Colorectal Cancer 'Common' and 'Uncommon'	
	Web Pages	p.118
	Comprehension Questions for Canadian Cancer Society	
	General Web Pages	p.121
Appendix E:	Introductory Research Letter	p.125
Appendix F:	Consent Form	p.127
Appendix G:	Recruitment Poster	p.128
Appendix H:	General Demographic Questionnaire	p.129
		P.12)
	Functional Health Literacy (Prose / Numeracy) Assessment: STOFHLA	p.133
Appendix J:	<b>General Context Numeracy Assessment</b>	p.136

Health Context Numeracy Assessment	p.137
Math Anxiety Assessment	p.138
Numeracy Skills and Anticoagulation Control	<b>p.14</b> 0
Representative Statistics	p.141
	p.154
1	Math Anxiety Assessment Numeracy Skills and Anticoagulation Control

# **List of Figures**

Figure 1.	Study Components on the Assessment of Health Literacy and Risk	
Figure 2.	Moderator Relationship	p. 62

# **List of Tables**

Table 1.	The Relationship Between Formal Education and Literacy Level	<b>p. 2</b> 1
Table 2.	Description of Participant Demographics	<b>p.</b> 54
Table 3.	Non-Parametric Correlations Between the Three Different Numeracy Assessment Measures	p. 59
Table 4.	Prose Literacy, Numeracy, and Math Anxiety Assessment Total Gender Specific Scores	p. 57
Table 5.	General Context Numeracy and Health Context Numeracy Regression Models	<b>p.</b> 61
Table 6.	<b>Moderator Analysis: Health Context Numeracy</b>	p. 63
Table 7.	Prose Literacy, Numeracy Literacy, and Math Anxiety Assessment Scores	p. 80
Table 8.	Explanatory Variables Regarding Comprehension of Web based Colorectal Cancer Information	p. 82

#### Introduction

Despite the overwhelming volume of health information and cancer research, conclusive answers with respect to cancer care continue to elude scientists and healthcare practioners. In lieu of precise answers, risk data, presented as numerical probabilities or broad descriptive terms, are used in response to patient questions regarding treatment options, quality of life, and life longevity. Consequently much of the disease treatment is dependent on consumer understanding of prescribed treatment directives, and comprehension of educational material.

The model of participatory healthcare assumes consumer contribution within healthcare decision-making. In fact, much of the success in the management of disease is dependent on consumer understanding of verbal or written information, participation in decision-making, a responsibility to self-care, and commitment to an established treatment plan. With the increased incidence in cancer, coupled with the advocated practice of patient participation, risk comprehension occupies a central position within the healthcare setting.

The therapeutic strategies of cancer care call for a strong educational component and access to cancer care information is an increasingly important contributor to quality care. Not surprisingly, the Internet serves as a significant source of health information. In fact, online searching for health information is one of the leading reasons for Internet use. Concerned about equitable access to quality healthcare, experts hypothesized that a lack of technological infrastructure and computer equipment would divide the population into those with superior quality of care and those without. Instead, the widespread lack of literacy skill is one of the discriminating factors.

The circumstances are serious - half of all Canadian adults comprehend only basic material that is simply laid out and are equally limited in both prose and numeric

literacy. As a result, numeric literacy or numeracy is garnering increased attention within healthcare. Specifically, inadequate numeric literacy limits consumers' ability to differentiate superior from inferior healthcare, to calculate treatment benefits, to correctly interpret risk reduction information, and to personalize risk data.

Experts emphasize practice as vital to the development and maintenance of numeric skills. Math anxiety, prevalent in more than half of the adult population, hinders numeracy development through avoidance of situations that require numeracy skill. Similarly, competency with prose literacy influences numeric ability. Development of numeracy skill is dependent, in part, on prior experience with the context of information; nonetheless, successful application of numeric skills to a wide variety of contexts reveals true numeric competency. Similarly, formal education, although strongly related to both prose and numeric skill, does not explain the 'literacy – education' relationship for a third of the adult population. Specifically, some individuals with higher education levels have low numeric functioning whereas others, with lesser education, have high numeric literacy skill. Most importantly, adequate numeric skill does not automatically translate to accurate comprehension of risk information.

As outlined above, a number of factors influence the development of numeracy skill, yet the weighting of each factor as a contributor to health numeracy skill and correspondingly, to comprehension of risk information, remains unresolved. Consequently, this research assessed whether and to what extent the literacy skill (prose and numeric) of a non-clinical, community dwelling population contributed to participant cancer risk comprehension. Cancer risk comprehension was evaluated against (1) math anxiety as a function of skill use or practice, (2) familiarity with the context of risk information, (3) level of formal education, (4) prose literacy skill, and (5) measured numeracy scores; these factors have independently been shown to

contribute to accurate understanding of risk or probability-based cancer information. The first chapter of this thesis provides background information to the issue of literacy (prose and numeracy) within a health context and risk comprehension of Internet based cancer information. Chapter 2 is based on a manuscript accepted for publication in a scholarly peer-reviewed journal and Chapter 3 is based on a manuscript submitted for review for publication. Chapter 2 summarizes participants' numeracy skill and further reports on the relationship between participant health context numeracy skill, prose health literacy, math anxiety, and level of formal education. Chapter 3 describes older adults' comprehension of online cancer risk information. This chapter depicts the variability of risk comprehension skill among community dwelling older adults as a function of prose health literacy skill, numeracy skill, level of formal education, math anxiety, and context of information. Chapter 4 provides a general discussion and interpretation of the overall study results, a discussion of study limitations, and concludes with a discussion of practice implications and directions for further research. The entirety of this work has been generously funded by a grant from the Canadian Institutes of Health Research (CIHR) to Drs. J.F. Arocha, and L. Hoffman-Goetz.

#### **CHAPTER 1: Literature Review**

# 1.1 Introduction

The Canadian Cancer Society (2006) states that colorectal cancer is one of the three leading causes of cancer among Canadians and the second leading cause of cancer deaths. In 2006, there will be an estimated 20,000 (10,800 men, 9,100 women) diagnoses and 8,500 deaths from colorectal cancer. Lacking widespread, population based, colorectal screening programs, increased consumer vigilance regarding personal symptom surveillance is encouraged. Information regarding colorectal cancer outlines risk factors, preventive strategies, and available screening techniques. In conjunction

with healthcare practitioners, consumers must assess their risk of disease and subsequently decide on 'best practices' appropriate to the determined risk. Literacy skill, particularly numeracy, is requisite to the accomplishment of this task.

This literature review will provide background information on: (1) general literacy and numeracy skill of Canadian adults, (2) health literacy, (3) numeracy within health, (4) prose literacy and numeracy in the elderly, (5) prose and numeric literacy and education, (6) health context numeracy and education, (7) numeracy and skill utilization, (8) numeracy and context of information, (9) measurement of health literacy and numeracy, (10) framework for risk comprehension, and lastly (11) a summary of the literature.

# 1.2 General Literacy

Literacy is defined as "the ability to understand and employ printed information in daily activities, at home, at work and in the community, to achieve one's goals and to develop one's knowledge and potential" (HRSDC, 2004). This definition dispels the traditional notion of literacy skill as a dichotomy (literate vs. illiterate) and introduces the concept of a continuum of proficiency inclusive of prose, document, quantitative, and problem solving skill (Statistics Canada, 2005a; HRSDC, 2004). Literacy constitutes "...a complex set of abilities needed to understand and use the dominant symbol systems of a culture – alphabets, numbers, visual icons - for personal and community development ... a technological society...includes multiple literacies such as visual, media and information literacy...focusing on an individual's capacity to use and make critical judgments about the information they encounter on a daily basis." (Centre for Literacy, 2006).

The complexity of contemporary society demands increasingly sophisticated literacy skill. The International Adult Literacy Survey (IALS) and the Adult Literacy

and Life Skills Survey (ALL) assessed Canadian adults on four literacy scales: prose literacy (ability to use and comprehend information from text material), document literacy (capability to identify and utilize information from documents such as job applications, schedules, maps, tables, graphs), numeracy (the knowledge and skills required to apply arithmetic operations, either alone or sequentially, to numbers imbedded in print material enabling for instance the ability to balance a cheque book, completing an order form, and to calculate interest on a loan), and problem solving (the ability to understand a problem situation and develop step-by-step resolution based on planning and reasoning) (Dingwall, 2000; Health Canada, 2003; HRSDC, 2004; Statistics Canada, 2000, 2005c).

Rather than describing individuals as literate or illiterate, literacy skills are a continuum ranging from quite limited to very high and falling into five broad literacy levels (Statistics Canada, 2005a, 2005c). Each literacy category has its own unique description of the five skill levels. Canadians have been ranked according to attained scores on responses to the administered literacy survey.

# 1.2.1 Prose Literacy

The International Adult Literacy and Skills Survey (IALSS) defines prose literacy as the knowledge and skill needed to understand and use information from texts including editorials, news stories, brochures and instruction manuals (Statistics Canada, 2005a). Prose skill levels are described as follows:

Level 1: Represents 14.6 % of Canadian adults. Level 1 corresponds to the lowest skill capacity. Adults within this lowest prose level are able to read short text to locate a single information item that is similar to the item given in the text.

Level 2: Represents 27.3 % of Canadian adults who read material that is simple, and clearly laid out. This category includes those who have adapted minimal literacy skill to their everyday experience but would experience little success if challenged with higher literacy demands. Adults are asked to locate

a single information item but with information distractors present, and to be able to compare and contrast easily identified information.

Level 3: Represents 38.6 % of Canadian adults and is the expected minimum literacy skill level of many countries. Skill expectancy includes the ability to integrate information from lengthy text and to use text information to formulate responses to questions in the presence of distracting information.

Levels 4 and 5: Represent 19.5 % of Canadian adults. Levels 4 and 5 are reported as aggregate scores because the small proportion of adults who achieve level 5 scores do not permit adequate accuracy in reporting. Functioning at levels 4 and 5 requires increasingly higher skill demanding the ability to integrate a number of sources of information to solve increasingly complex problems. Respondents are required to integrate or synthesize information from lengthy and complex text and to search for information in dense text containing many plausible distracters. Participants are also required to use specialized background knowledge.

Essentially, 42% of all Canadian adults have difficulty with very simple reading materials. These limitations are particularly pronounced among seniors, aged 55 years and older (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999; Health Canada, 2003; HRSDC, 2004). Thus, the difficulty with basic prose literacy is not only prevalent in the adult Canadian population but is of greater magnitude among certain subgroups, such as seniors, Aboriginal Canadians, and those with English as a second language (Statistics Canada, 2005a).

## 1.2.2 Numeracy

With increased societal complexity, global communication, and international trade, the conditions for numeracy (quantitative literacy) required for everyday functioning have increased (Dingwall, 2000; Paulos, 1989; Steen, 1990, 1999). Numeracy is one of four constructs within the larger concept of literacy (Statistics Canada, 2005a). Numeracy skills are necessary in order to effectively budget and manage finances, to maintain health (i.e., understand health related information related to decision making around medications, health risks, diet, and exercise), and to maintain a household (i.e.,

home repairs / renovation, mortgage, shopping) (Bunker, Houghton, & Baum, 1998; Dingwall, 2000; Epstein, Alper, & Quill, 2004).

Within the education sector, numeracy acts as the 'gatekeeper' to many other fields of investigation (i.e., social sciences, health studies) and is pre-requisite for advanced learning within academia. Furthermore, numeracy is a primary measure of what constitutes contemporary citizenry, enabling an understanding of matters related to taxes, expenditures, interest rates, employment levels, public opinion polls, and elections. Finally, numeracy is an increasingly vital skill for work-related purposes such as measuring, scheduling, tracking and monitoring, and managing revenues /expenditures (Dingwall, 2000; Steen, 1999).

The ability to recall mathematical concepts does not necessarily reflect full numeracy skill, which involves the capacity to successfully apply numeric understanding within contextually different situations (Steen, 1999; Weinstein, 1999). Current evidence suggests that many North Americans struggle with numeracy skills (Adelsward & Sachs, 1996; Dingwall, 2000; Health Canada, 2003; Statistics Canada, 2005a; Weinstein, 1999). Behaviours linked to numeracy success include the ability: (1) to recognize task related mathematical information in a variety of presentation formats (pictures, numbers, symbols, formulae, diagrams, charts, maps, graphs, tables, and text), (2) to appropriately utilize the information (measurement, calculation, estimation), (3) to decipher and translate the information within the context presented, and (4) to communicate understanding of the numeric message (Dingwall, 2000; Steen, 1999).

Numeracy is more than an understanding of mathematics (Steen, 1999, 2001b).

Numerate individuals need both mathematics and numeracy to successfully navigate the complexities of everyday life. In effect, numeracy success is dependent on an aggregation of knowledge (arithmetic, measurement, data analysis), skills (analysis and

comprehension of numerical information buried within text), strategies (problem solving), and attitudes (confidence) that individuals must convey in situations involving numbers (Dingwall, 2000). It is concerning that 55% of Canadian adults score in the lowest two categories of numeracy skill levels (Statistics Canada, 2005a). Numeracy skill is depicted as a continuum of proficiency on a five level scale. Those scoring in level one represent the weakest numeracy skill whereas adults with the greatest numeracy capability are rated as level five. The five progressive levels are described below.

Level 1: Represents 19.5% of Canadian adults. An understanding of basic numerical ideas by counting, sorting dates, simple arithmetic operations, in a familiar context with little text shows competency.

Level 2: Represents 30.3% of Canadian adults. Tasks are simple and related to basic mathematical concepts embedded in familiar concepts that are one step or two step processes.

Level 3: Represents 33.4% of Canadian adults. Demonstrated skill involves understanding mathematical information in diverse formats: numbers, symbols, maps, graphs, and text. Knowledge of patterns and relationships, and ability to interpret proportions, data, and statistics embedded in simple texts.

Level 4/5: Lacking sufficient level 5 responses to disaggregate level 4 and 5, scores were combined scores and represent 16.9% of Canadian adults. Competency requires an understanding of a broad range of mathematical information represented in a variety of ways with increasing complexity of text or a lack of familiarity (i.e. use of abstract and formal mathematical and statistical ideas to be able to draw inferences, or provide justification for responses).

Important in successfully navigating the healthcare system, numeracy provides tools that allow individuals to think for themselves, to ask intelligent questions, and to assertively and confidently manage authority (Steen, 1999).

Many Canadians function below the expected minimum level of prose and numeracy skill and are challenged by increasingly complex material. Further delineation of the literacy concept recognizes specialized skill subsets in the areas of scientific, technological, cultural, media, computer, and health literacies (Kickbusch,

2001). In essence, literacy represents a continuum of proficiency, providing individuals with the foundational skills for the facilitation of personal and community development.

# 1.3 Literacy and Health

Typically, healthcare professionals have not considered the influence of literacy on patient care and, until recently, have had no compelling reason to study the implications of literacy on patient health status (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999; Woloshin, Schwartz, Moncur, Gabriel, & Tosteson, 2001). Even more recently, few medical residents and medical students recognized the significance of low health literacy related to patient care even when clues to limited health literacy were made obvious (Powell & Kripalani, 2005). Health literacy is used to describe literacy contextualized within healthcare and is a fundamental determinant of health. Health literacy is both a contributor to poor health and an intervention for improved health (Health Canada, 2003; IOM, 2004; Nutbeam, 2000; Statistics Canada, 2000). Definitions of health literacy have evolved from simply being "...the ability to read, understand, and act on healthcare information" (CHCS., 2000) into multifaceted, comprehensive models (Nutbeam, 2000; Zarcadoolas, Pleasant, & Greer, 2005). Specifically defined, functional health literacy consists of a constellation of skills that includes the ability to perform basic reading and numerical tasks specific to the healthcare environment (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999). Adequate health literacy enables individuals to understand oral and written information about healthcare issues, follow written and numerical directions regarding their therapeutic regimens and diagnostic tests, ask pertinent questions of healthcare providers, report past medical history, and contribute to problem solving related to their care (Parker, Baker, Williams, & Nurss, 1995). Functional health literacy, in assuming adequacy in comprehension and understanding of both written and verbal communication, presupposes an ability to understand and act upon directives from physicians and other healthcare practioners (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999). Similarly, the Institute of Medicine (IOM) defines health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (IOM, 2004, p. 4).

Health literacy involves the "...cognitive and social skills, which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health ... [It also] implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions" (Nutbeam, 2000, p. 264). This multi-faceted definition attributes both cognitive as well as behavioural aspects to health literacy. Adequate health literacy is characterized by the ability to access, comprehend and to take action on health information with the ultimate goal of promoting or maintaining good health. This definition also addresses the broader determinants of health - the social, economic, and environmental determinants in order to improve personal and community health. Further evolution of the concept identifies a health literate person as one with the proficiency of skill that permits the application of health information to diverse and novel situations (Zarcadoolas et al., 2005). Here health literacy is defined as "...the wide range of skills, and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase quality of life" (Zarcadoolas et al., 2005, p. 197). Characterized by four central literacy subject areas this model includes: fundamental literacy, science literacy, civic literacy, and cultural literacy. The basis of this model consists of fundamental literacy as basic reading, writing, speaking, and numeracy skills. Science literacy is

tied to competence with science and technology inclusive of knowledge of basic science concepts, an understanding of technology, and comprehension of scientific uncertainty. Civic literacy refers to the skills that enable community members to become actively engaged in and aware of public issues and decision-making processes. Further categorization of civic literacy includes media literacy skills, knowledge of government, and recognition that personal choices influence and impact on public health. Finally, cultural literacy refers to the use of beliefs, customs, and social identity for the interpretation of and actions regarding health information. There is a responsibility by the communicator to frame health information in a way that accommodates cultural beliefs and customs. This expanded model of health literacy also goes beyond reading, writing, and numeracy skill to include the wider spectrum of knowledge domains that impact on individual and community health.

Recognizing the multiplicity of definitions and use of the term, "health literacy", researchers conducted a concept analysis to identify defining characteristics of the term (Speros, 2005). Concept clarification is essential for meaningful debate on the issue, for comparison of research findings, and for effective intervention planning. The intention was to clarify the meaning of health literacy, and to promote consistency of use among healthcare professionals and researchers. The defining attributes (characteristics most frequently associated with the concept and are repeatedly referenced in conjunction with the term) of health literacy are reading skills (i.e., focusing attention, using context to understand new terms, word recognition, organizing and integrating new information), comprehension (ability to use context and prior knowledge to aid understanding), and decision-making (ability to problem solve). Antecedents (events or incidents consistently preceding the occurrence of the concept) of health literacy include: (1) literacy skill (reading comprehension and computational ability), and (2) a health related experience such that individuals with adequate health

literacy require some exposure to the language of healthcare. A health related encounter also enables the development of a mental framework that permits cognitive organization of further healthcare experiences (Speros, 2005). Essentially, health literacy comprises the processes of reading, comprehension, and decision-making within the specialized content area of health. General literacy skill and healthcare experience are requisite antecedents to the development of health literacy.

A pioneering 1995 U.S. study estimated the prevalence of functional health literacy in individuals presenting for care at two urban public hospitals (Williams, Parker, Baker, Parikh, Pitkin, Coates, & Nurss, 1995). Using the Test of Functional Health Literacy for Adults (TOFHLA), more than one third of study participants had inadequate or marginal health literacy. Individuals of this rank were least likely to comprehend even the simplest written patient education materials. Without assistance from health educators, nurses, or physicians, these individuals were considered at risk for: (1) making an error in taking medications, (2) having difficulty in following diet and exercise instructions, and (3) having little understanding of established care plans.

Baker et al. (1998) confirm the work of Williams (1995) and further showed that 48% of U.S. adults had inadequate or marginal health literacy skills. Functional health literacy also predicted rate of hospitalization: patients with inadequate health literacy were twice as likely as patients with adequate literacy to be hospitalized (Baker, Gazmararian, Williams, Scott, Parker, Green, Ren, & Peel, 2002; Baker, Parker, Williams, & Clark, 1998). After adjusting for age, gender, race, self-reported health, socioeconomic status, and health insurance, individuals with inadequate health literacy were twice as likely to be hospitalized than others with adequate literacy skills. Furthermore, individuals with inadequate and marginal health literacy utilized more hospital emergency department services, knew significantly less about their diagnosed chronic disease condition, were less likely to read written medical information and less

likely to seek out written health information than individuals with adequate health literacy (Baker, Gazmararian, Williams, Scott, Parker, Green, Ren, & Peel, 2004; Gazmararian, Williams, Peel, & Baker, 2003; Koo, Krass, & Aslani, 2006). Health literacy skill also mediated the relationship between education and diabetic self care behaviour such that poor health literacy predicted poor diabetic glycemic control (Schillinger, Barton, Karter, Wang, & Adler, 2006). Relative to patients with adequate health literacy skill, low health literacy also compromised verbal communication of health information. Low health literate patients reported less clarity of information, less comprehension of the condition, and a poorly explained process of care (Schillinger, Dean, Bindman, Wang, Stewart, & Piette, 2004). Poor health literacy (TOFHLA) has been an associated with limited knowledge regarding HIV infection and linked to misperceptions regarding HIV treatment (Kalichman, Benotsch, Suarez, Catz, & Miller, 2000). Asthma patients with low health literacy (TOFHLA) were less satisfied with the status of their asthma condition, expressed negative feelings regarding their treatment results, and were less willing to participate in decisions regarding their own care (Manusco & Rincon, 2006). Similarly, individuals with low health literacy were more likely to report poor health than those with self reported good health status (Baker, Parker, Williams, Clark, & Nurss, 1997). An ALSS comparison of literacy skill and health status revealed that self-reported healthy individuals had significantly higher prose and numeracy scores relative to respondents with poorer self-reported health (Statistics Canada, 2005c).

Functional health literacy is a critical component of risk communication across the continuum of cancer care (Davis, Williams, Marin, Parker, & Glass, 2002). This is especially true within the context of genetic based diseases where a considerable degree of uncertainty can be attached to a risk estimate (Eiser, 1998; Hanoch & Pachur, 2004). Genetic counseling and breast cancer screening are examples of such situations.

Genetic testing is inherently associated with uncertainty where positive genetic test results imperfectly predict disease occurrence (false positive) and disease absence (false negative) (Hanoch & Pachur, 2004). Adults with low health literacy were less likely to obtain preventive screening, had less knowledge about their diagnosed cancer, were more likely to present with advanced stages of cancer illness, and to experience higher rates of disease mortality (Davis et al., 2002; Garbers & Chiasson, 2004; Nurss, Parker, & Baker, 1995). Similarly, low functional health literacy was associated with less knowledge about colorectal cancer screening and reported lower rates of screening prevention (Guerra, Dominguez, & Shea, 2005). The relationship between functional health literacy and colorectal cancer screening knowledge was influenced by level of education and ethnicity. Individuals of Latino ethnicity and with lower formal education were significantly more likely to have less knowledge of colorectal cancer screening and lower rates of cancer screening (Guerra et al., 2005).

It is important to note that most initial prevalence estimates of health literacy skill were derived from U.S. with populations that included underprivileged and minority patients. Almost half of the early prevalence studies included individuals of African-American and Hispanic descent (Baker, Williams, Parker, Gazmararian, & Nurss, 1999; Parker et al., 1995; Williams et al., 1995). A review of the health literacy literature revealed that those with lower income, lower education, higher age, and of visible minority (i.e., African Americans, Hispanic Americans) revealed lower health literacy skill (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005). The U.S. national adult literacy survey also found low literacy skill associated with those who were elderly, immigrants, belonging to a visible minority group, of low income, and low education (NCES, 2006).

# 1.3.1 Numeracy and Health

Similar to general numeracy, health numeracy is represented within the larger concept of functional health literacy. Health numeracy has been defined as "the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions" (Golbeck, Ahlers-Schmidt, Paschal, Dismuke, 2005b, p. 375). Health numeracy has been modeled into four categories of basic, computational, analytical, and statistical skill (Golbeck et al., 2005b). Basic health numeracy includes the ability to identify numbers and comprehend quantitative data with no number manipulation (e.g., correctly identify the date of a scheduled healthcare appointment). Computational numeracy involves skill in simple arithmetic whereas analytical skill requires interpretive skills characteristic of the ability to determine whether scores fit within an established range. The final level of health numeracy skill, 'statistical', requires an understanding of basic biostatistics (i.e., probability, life expectancy, risk).

Health related information often involves quantitative expressions of fractions, percentages, frequencies, and terms like 'outcome likelihood' (e.g., survival rate of 95%), drawing on numeric literacy skills (Burkell, 2004; Detsky & Redelmeier, 1998; Lipkus, Samsa, & Rimer, 2001; Paulos, 1989). The following quote further illustrates the significance of numeracy within health information.

"In Canada, scientific evidence shows that colorectal cancer deaths could be reduced by 17 per cent if 70 per cent of Canadians between the ages of 50 and 74 had a fecal occult blood test (FOBT) every two years. This is a potentially significant drop in deaths from colorectal cancer... Although some informal screening is taking place, there is no organized colorectal screening program in Canada." (Canadian Cancer Society, 2006)

The numeracy knowledge required to interpret the above information is contextualized within the disease cancer. Confronted with this information and without requisite numeracy skills, the task of decision-making regarding preventive colorectal cancer screening may be more difficult and the determination of personal risk more challenging for some individuals. A content analysis conducted on three prominent Internet based breast cancer sites assessed the amount, type, and level of posted numeracy information (Ahlers-Schmidt, Golbeck, Paschal, Zackula, Taylor, 2006). The information found within the breast cancer Internet sites revealed a high frequency of numeracy concepts. In addition, the posted information required understanding of probability statements, life expectancy, and risk. The online numeracy references presented advanced numeracy concepts requiring a highly sophisticated level of comprehension that would perhaps be too advanced for the intended audience (Ahlers-Schmidt, Golbeck, Paschal, Zackula, Taylor, 2006).

Similar to observations about general numeracy skills in the population, numeracy skills contextualized to health are also limited. Fewer than 20% of adults (≥ 40 years) who participated in breast and colon cancer screening were able to correctly answer any of the three general context numeracy questions presented to them (Lipkus et al., 2001). The majority (60%) of adults answered either none or only one of the three questions correctly. In fact, only 18% of participants answered all three questions correctly. Sheridan et.al., (2003) found that despite expressed confidence, 71% of adults correctly answered one or none of three general context numeracy questions, with only 2% correctly answering all three. Women (40-85 years of age) belonging to two primary care clinical practices were asked these same three general context numeracy questions. A substantial proportion experienced difficulty. Thirty-one percent of women answered none or only one of the general context numeracy

questions. Alternatively, 41% of participants answered all three numeracy questions correctly (Davids, Schapira, McAuliffe, & Nattinger, 2004).

Men and women had greater success responding to numeracy questions that were contextualized to healthcare (Lipkus et al., 2001). Despite this improved performance, mistakes were made on seemingly simple operations (e.g. asking respondents to indicate which value, 1 in 100 or 1 in 10, represented a higher health risk). In fact, as many as 20% of the study participants incorrectly responded to the task requiring judgment of risk magnitude. This finding was particularly troubling given that these same numeracy tasks were integrated into decision aids used to support shared decision making (Lipkus et al., 2001).

Low numeracy has been associated with poor medication (anticoagulation control) management for at risk adults (Estrada, Martin-Hryniewicz, Barnes-Higgs, Collins, & Byrd, 2000). There is also evidence that individuals with low numeric skill are less able to accurately assess and personalize health risk. For example, Schwartz et al. (1997) found that most women (27-88 years) with low numeric skill struggled to correctly interpret risk reduction data when asked to estimate their risk of death from breast cancer with and without screening mammography. Even with available data, (e.g., relative risk reduction, absolute risk reduction) most women overestimated the effectiveness of mammography screening. In fact, the relationship between estimate accuracy and numeracy persisted even after adjusting for age, income, level of education and framing of the risk information. Women with low numeracy skill were unable to accurately assess their risk of breast cancer using two different scales for the measurement of risk perception (Schapira et al., 2004). Similarly, women who scored low in numeracy were more likely to overestimate their lifetime breast cancer risk; this finding suggests an important link between numeracy skills and the ability to accurately interpret risk estimates (Davids et al., 2004). Highly numerate individuals (assessed

using a three question general context numeracy instrument) were more likely to retrieve and use appropriate measures of probability and to transform numbers from one format to another than less numerate adults (Peters, Vastfjall, Slovic, Mertz, Mazzocco, & Dickert, 2006b).

Poor numeric skill of incident head and neck cancer patients negatively influenced self-reported quality of life (Schwartz, Woloshin, Black, & Welch, 1997). Given that survival differences between surgical and non-surgical interventions for head and neck cancer are difficult to determine, greater attention has been directed to patient's reported quality of life after treatment. Utility assessment scores provide insight into self reported quality of life. For example, participants were asked to report what chance of death they would be willing to accept in order to be free of symptoms from their illness. Utility measure scores range from 0 (worst possible health state) to 1 (the best possible outcome) and represent a measure of quality of life through the value (0-1) patients assign to their state of health. Participants reporting 'good' quality of life would also be expected to report high utility scores. Innumerate patients' responses to utility measures were of questionable validity. A significant number of low numeracy participants who assessed their quality of life as 'bad' reported high utility scores. For those with strong numeracy skills "...quantitative messages may convey information concisely and with great precision. However ...for many persons, quantitative expressions may have no meaning or may represent useless and potentially confusing information" (Schwartz et al., 1997). The relationship between numeracy and risk comprehension was further investigated by Weinstein et.al., (2004). Estimates of colon cancer risk were greatly overestimated, where adults scoring low in numeracy were more likely to give unrealistically high estimates of risk. Yet, regardless of numeric skill, when presented with personalized risk information, participants' initial estimates of risk remained relatively unchanged. One explanation included an inadequate

assessment of numeracy using only 2 rather than 3 or 8 numeracy questions. Participants were doubtful of the personalized feedback regarding cancer risk and persisted in overestimating their personal risk estimates (Weinstein, Atwood, Puleo, Fletcher, Colditz, & Emmons, 2004).

Concerned with optimizing informed decision-making, the numeracy skill of 328 cancer patients considering participation in phase 1 oncology clinical trials was assessed (Weinfurt, DePuy, Castel, Sulmasy, Schulman, & Meropol, 2004). Advanced cancer patients numeracy skill was evaluated using a single question assessment. The assessment question was as follows: "The following question involves a hypothetical situation in which your doctor is describing a new treatment. Imaging that your doctor says this new treatment controls cancer in 40% of cases like yours. How do you interpret what the doctor is saying"? Participants were asked to choose one correct answer from seven multiple-choice options. While 72% of participants were able to correctly respond to the numeracy task, approximately one third failed to convert a percentage to a frequency (40% = 40/100). These findings reinforce the need for effective assessment and identification of low numerate individuals in consideration of improving communication and comprehension of potential risk and benefits of treatment.

#### 1.3.2 Prose Literacy and Numeracy in the Elderly

More older than young adults demonstrate poor health literacy skill (Baker, Gazmararian, Sudano, & Patterson, 2000; Baker et al., 2004; Fuller, Dudley, & Blacktop, 2001; Gazmararian, Baker, Williams, Parker, Scott, Green, Fehrenbach, Ren, & Koplan, 1999; Williams et al., 1995). This finding is especially concerning for an already vulnerable population who "have worse health, fewer economic resources, and less ability to successfully navigate the healthcare system and complete personal

healthcare tasks" (Baker et al., 1998). Estimates of population prevalence of inadequate or marginal health literacy among seniors range from 34% of individuals aged 65 years + (Baker et al., 2004; Gazmararian et al., 1999; Wolf, Gazmararian, & Baker, 2006) to 81% of individuals 60 years + (Williams et al., 1995). Variation in reported prevalence rates may reflect differences in race, language skills, age, years of school completed, and occupation of the populations surveyed (Baker et al., 2004; Gazmararian et al., 1999; Wolf et al., 2006). The relationship between diminished health literacy and increased age persists even after adjusting for cognitive functioning, sex, race, ethnicity, and education (Baker et al., 2000). Assessed differences in reading frequency, visual acuity, chronic medical conditions, and health status were unable to account for this inverse relationship. Inadequate health literacy has been linked to poorer physical and mental health among older community-dwelling adults (Wolf et al., 2006). Health encounters are compromised due to inferior communication processes resulting from poor functional health literacy (Wolf et al., 2006). Notably, inadequate health literacy skill represents an important barrier to elderly patients' understanding of diagnoses and treatment protocols (Nurss et al., 1995; Williams et al., 1995).

Although the range of numeric skill within the elderly is diverse, there is greater representation of those with limited numeric ability. A numeracy assessment of postmenopausal women revealed that 26% of women (50-79 years) answered none to one of the three general context numeracy assessment questions correctly, 36% answered two questions correctly, and 38% answered the three questions correctly (Woloshin et al., 2001). Of men and women, age 50-80 years, 2% answered the three general context numeracy questions correctly, 28% answered two correctly, and 71% answered one or none correctly (Sheridan, Pignone, & Lewis, 2003; Sheridan & Pignone, 2002).

## 1.4 Prose and Numeric Literacy and Education

Available evidence suggests a strong relationship between literacy skill and education level (Table 1) (HRSDC, 2004; Statistics Canada, 2005a). Most adults without secondary school education are at the lowest literacy level. Adults who fit into literacy level 2 have some high school education and those who have completed high school typically perform at literacy level 3. Approximately 40% of Canadians with a community college or a university degree fit into literacy level 3. Almost twice as many university graduates than college graduates function at level 4/5 (HRSDC, 2004; Statistics Canada, 2005c).

Table 1. The relationship between formal education and literacy level in Canada

Literacy Level	<b>Educational Attainment</b>
Level 1&2	Some high school or less
Level 3	Mainly high school graduates; some community college and university graduates
Level 4/5	Some community college; mainly university graduates

Despite this relationship, approximately one quarter of adults do not fit the pattern described above. Some who have not graduated from high school have literacy skills at level 3 or above whereas some individuals with community college diplomas function at the lowest literacy levels (HRSDC, 2004; Statistics Canada, 2005c). For example, 22% of university prepared adults operate below the minimum level of skill expectancy (Statistics Canada, 2005c). Finally, individuals who do not complete high school have exceptionally poor quantitative skills (HRSDC, 2004; Statistics Canada, 2005c). While education plays a key role in the development of individual prose and numeracy skills, evidence suggests that the relationship between education and literacy skills involves

other factors (i.e., continued education, occupational experience, motivation, cognitive changes) that contribute to literacy skill acquisition, preservation, and loss over the course of a lifetime (Statistics Canada, 2005c). Although correlated, educational attainment as a proxy estimate of adult literacy skill can result in considerable error (Statistics Canada, 2005c). That younger cohorts have received a greater number of years of formal schooling compared to older cohorts, may contribute to the observed variation in literacy skill (Statistics Canada, 2005c).

Some investigators speculate that health literacy is a more accurate measure of educational attainment than years of school completed (Baker et al., 1999). Rather than 'years of school', "...health literacy may be an indicator of someone's ability to acquire new information and complete complex, cognitive tasks" (Baker et al., 1998, p.797). Patients assessed for functional health literacy skill revealed inconsistencies similar to those found in the relationship between general literacy skill and education level. Inadequate functional health literacy was associated with  $\leq 8$  years of schooling. Alternatively, post-secondary education was more closely aligned with adequate functional health literacy. However, functional health literacy is difficult to predict for individuals who have between 9 to 12 years of school (Baker et al., 1999). For example, 23% of individuals with inadequate health literacy completed high school, whereas 23% of individuals with adequate health literacy did not (Baker et al., 1998; Williams et al., 1995). This discrepancy reflects the findings of the ALSS where exceptions to the literacy – education relationship also exist. A number of factors may account for this inconsistency, for example the improvement in educational quality over time may account for differences between age cohorts (Statistics Canada, 2005c). Similarly, the attainment of a high school diploma does not guarantee knowledge and understanding of a specialized subject area such as healthcare (Statistics Canada, 2005c). For some individuals, concepts reviewed within the academic setting (i.e.,

mathematics) may not translate to the 'real world' setting of healthcare. In addition, retention of literacy skills learned within formal educational settings may or may not be reinforced and over time may become greatly diminished or alternatively greatly improved.

The decline in literacy skill with increasing age may be a function of the level of formal education. In fact, World War II is the historical event that divides the Canadian population with respect to educational achievement (HRSDC, 2004). Approximately forty percent of Canadians over 65 years of age have not completed primary school while only 4% of adults aged 26 to 35 have less than primary school preparation. The largest proportion of Canadians over 65 years function at Level 1, limiting their ability to successfully navigate the complexities of a knowledge-based society (Statistics Canada, 2005c). Yet, even when educational differences are accounted for in the analysis, literacy skill continues to deteriorate with increasing age (HRSDC, 2004; Statistics Canada, 2005a). According to HRSDC (2004), "a large portion of the population is restricted in daily activities and often dependent on others for help. Poor literacy skills may lower seniors' quality of life and increase their health and safety risks, both of which have high human and social services costs" (HRSDC 2004, p.e2). Similar declines have occurred with functional health literacy and increased age. In fact, a markedly higher prevalence of inadequate and marginal health literacy is found in males and females ≥ 85 years (Gazmararian, et al., 1999; Williams et al., 1995). Health literacy declined with increasing age even after adjusting for reading frequency, chronic medical conditions, and cognitive performance (Baker et al., 2000). Literacy (prose / numeracy) skill utilization or practice contributes to the retention of cognitive skills over time, making life experience an influential factor between aging and skill development and maintenance (Statistics Canada, 2005c).

## 1.4.1 Education and Numeracy in Healthcare

Despite the evidence of association between greater years of schooling and enhanced numeracy skill, detailed analysis reveals some discrepancy in this relationship (Sheridan et al., 2003). Even those considered well educated in terms of attained years of schooling have deficiencies in numeric skill. Approximately 25% of women assessed with poor numeracy skill had at least a high school education, 25% had some college education, and 47% had college or postgraduate degrees (Woloshin et al., 2001). An investigation assessing the impact of numeracy skill on breast cancer screening, found that fifty-eight percent of older women, most high school graduates (96%), scored poorly on a general context numeracy assessment (Schwartz et al., 1997). Of patients (men and women) at a general medical clinic, 60% of those with the lowest numeric rating had 'some college education' (Sheridan et al., 2003). Thus, as with general numeracy skill, the relationship between attained education and numeracy contextualized to health is unclear.

Interestingly, experts indicate that most children have acquired basic probability concepts by the age of 12 years even without formal instruction (Konold, Pollatsek, Well, Lohmeier, & Lipson, 1993). Moreover, basic probability concepts can be taught to undergraduate students in less than one hour (Konold et al., 1993). Differentiating between mathematics and numeracy may clarify these findings. Numeracy is more than and different from basic mathematics (Steen, 1999; 2001b). Numeracy expertise is differentiated from mathematics through the application of knowledge (arithmetic, measurement, data analysis), skills (analysis and comprehension of numerical information buried within text), strategies (problem solving), and attitudes (confidence) to successfully accomplish everyday tasks and functions rather than a focus on tasks of mathematical abstraction.

## 1.5 Numeracy and Skill Utilization

Perhaps most significant is the notion that 'numeracy' "is a practice driven competence rather than abstract knowledge of 'mathematics'" that is essential to daily living and working (Adelsward & Sachs, 1996; Burkell, 2004). Paradoxically, numeracy as a practical skill is rarely reinforced, either within the educational system or at home (Burkell, 2004; Steen, 1990, 1999). Yet, numeracy success is dependent on practice and increased opportunity of skill utilization. However, there is also strong evidence that math anxiety invokes apprehension with respect to working with numbers and is widespread in academic, private, and social settings (Ashcraft, et al., 2001; Hunsley, 1987).

Those with expressed mathematical anxiety convey faulty beliefs and communicate negative attitudes regarding personal problem solving abilities (Ashcraft 2002). Not only will math-anxious individuals seek to avoid situations that demand math skills, there is evidence that response accuracy is sacrificed for speed of response (Ashcraft & Faust 1994). In fact, those with high math anxiety scores avoid situations that involve number calculations, are less inclined to seek out opportunities to utilize mathematical skills, and are assumed to have had less practice and opportunity for skill utilization. Within the context of cancer risk communication, there are no published studies investigating the influence of math anxiety on numeracy skill.

Woloshin et al. (2005) assessed patients' interest and confidence in using medical statistics. From this work, two new measures, the STAT-Interest and the STAT-Confidence, were developed and tested for scale reliability and validity (Woloshin, Schwartz & Welch, 2005). The STAT-Interest scale included four items and the STAT-Confidence scale included three. All test items revealed good psychometric properties with low item non-response, broad response range, good test-retest reliability and respectable internal consistency reliability (Woloshin et al., 2005).

The majority of respondents expressed great interest in medical statistics and confidence in their ability to interpret medical data. Assessed interest and confidence in using medical statistics was poorly associated with participants' actual interpretation of medical data. Researchers concluded that participant feelings of confidence and interest in health statistics were inadequate proxy measures for numeracy skill. Thus, caution is advised in inferring numeric ability from these assessments.

#### 1.6 Numeracy and Context of Information

Numeric skill is dependent on prior knowledge and familiarity of the situation (Health Canada, 2003; IOM, 2004). Yet, the work of Lipkus et al. (2001) is at variance with this claim. Men and women completed 3-question and 8-item (expanded) numeracy instruments (see Appendix A). The expanded 8-item instrument measured mathematical operations (e.g., convert percentages to a proportion) within the context of health. This instrument was used to understand how well people could: (1) discern differences in magnitude of health risks, (2) differentiate and perform simple mathematical operations on risk magnitudes using percentages and proportions, (3) convert percentages to proportions, (4) convert proportions to percentages, and (5) convert probabilities to proportions (Lipkus et al., 2001). There was no evidence that a change of context ('mathematical' context vs. health context) affected respondent performance since the same numeracy construct was being assessed. All numeracy items reflected the central construct of global numeracy indicating that general context measures of numeracy effectively assess numeric performance within the health risk domain (Lipkus et al., 2001).

## 1.7 Measurement of Literacy and Numeracy in Health

Many researchers suggest that proper assessment of, and subsequent intervention with patients' literacy skills will enhance health status through improved comprehension of diagnosis, treatment, and self management (Davis, Michielutte, Askov, Williams, & Weiss, 1998). Experts, concerned with response validity to questionnaires, interviews, and informed consent, suggest that health literacy and numeracy play a significant role in consumer comprehension and informed decision-making (Davis et al., 1998; Woloshin et al., 2001). However, there are few studies that measure health literacy / numeracy as outcome variables of interest (Davis et al., 1998; Golbeck, Ahlers-Schmidt, Paschal, & Dismuke, 2005b).

Arguably, there are currently no formal standardized methods to comprehensively assess consumer health literacy (Davis & Wolf, 2004). The most widely used health literacy (prose and numeracy) assessment instruments (Test of Functional Health Literacy for Adults (TOFHLA) or the shortened version (STOFHLA) of this same test) have been applied to research situations with little available evidence of their appropriateness for screening in clinical settings (Davis & Wolf, 2004). It appears that numeracy has been operationalized into two different measurement protocols. As a component of functional health literacy, numeracy is measured by the Test of Functional Health Literacy for Adults (TOFHLA) (Parker et al., 1995). Alternatively, a number of studies have utilized a 3 question general numeracy protocol to specifically assess the numeric concept of risk and probability (Lipkus et al., 2001; Schwartz et al., 1997; Sheridan et al., 2003). However, reading comprehension may be fundamentally tied to an understanding of numerically based problems. An assessment tool, such as the TOFHLA, is essential in this case. The following section describes the key health literacy measurement tools used in research.

A health based, literacy /numeracy test is the TOFHLA (STOFHLA) (Baker et al., 1999; Davis et al., 1998; Parker et al., 1995). Categorized as a comprehension assessment, the TOFHLA consists of two parts: reading comprehension and numeric knowledge. Using a modified Cloze-type format where every fifth to seventh word in the given text is omitted, the reader selects from multiple-choice responses, one of which is correct and three of which are similar but grammatically or contextually incorrect. The Cloze procedure measures individual comprehension of printed information whereby participants complete sentences where a random deletion of words or a deletion of words at a determined interval (i.e., every 5<sup>th</sup> or 7<sup>th</sup> word) of a passage of text has occurred (Taylor, 1953). TOFHLA measures participant comprehension of text passages based on real healthcare situations.

The TOFHLA numeracy items assess a patient's ability to comprehend directions for taking medicines, monitoring blood glucose, keeping clinic appointments, and gaining financial assistance. The reading comprehension and numeracy scores are equally weighted in the final TOFHLA score, which ranges from 0-100. Scores of 0-59 represent inadequate health literacy skill, scores of 60-74 indicate marginal health literacy, and 75-100 indicates adequate literacy. Recommended as a research tool rather than a clinical tool, the TOFHLA takes up to 22 minutes to administer and is recognized as the most useful health literacy assessment tool (Davis et al., 1998).

Baker et.al.(1999) developed a shortened form of the TOFHLA. The STOFHLA (Appendix I) consists of a reading comprehension section containing 2 prose passages that are derived from realistic U.S. healthcare episodes: (1) preparation for upper gastrointestinal testing and (2) understanding consumer rights and responsibilities in applying for Medicaid. The readability levels of the 2 passages as measured by the Gunning Fog Index are equivalent to grades 4 and 10 respectively (Baker et al., 1999). The Gunning Fog Index is an assessment of readability based on

the average number of words in a sentence and the number of polysyllabic words contained within the text. The Gunning Fog Index indicates the number of years of formal education that a person requires in order to easily understand the text on the first reading. In total, there are 36 Cloze items that measure an individual's ability to read. Each of the 36 items in the reading comprehension section is assigned a score of 2 for a maximum score of 72 points.

The STOFHLA also contains four numeracy items that assess an individual's ability to understand numbers within the context of healthcare. Numeracy test questions assess comprehension of prescribed drug dosages, monitoring blood glucose, and scheduling clinic appointments. Cue cards or labeled prescription bottles are presented to the consumer who then responds to questions that are posed orally from the test administrator. Each of the four numeracy items are assigned a score of 7 points for a possible 28 total points.

As with the TOFHLA, the STOFHLA has a combined total score ranging from 0 to 100. Individuals scoring 0 to 53 fall within the inadequate health literacy category. Those scoring 54 to 66 are considered marginally health literate, and those with scores ranging from 67 to 100 have adequate health literacy. The STOFHLA shows adequate internal consistency (Cronbach's  $\alpha=0.68$ ) for the numeracy items and good internal consistency (Cronbach's  $\alpha=0.97$ ) for reading comprehension. The correlation was reasonable between the STOFHLA and the REALM (Rapid Estimate of Adult Literacy in Medicine) at 0.80 (Baker et al., 1999). The STOFHLA is reliable and valid relative to the TOFHLA but with increased practicality. The STOFHLA provides an efficient measure of functional health prose and numeric literacy.

A number of studies have utilized a 3-question general protocol to specifically assess the concept of risk and probability (Lipkus et al., 2001; Schwartz et al., 1997;

Sheridan et al., 2003). This instrument measures an individual's ability to utilize quantitative information as related to competence with basic probability and numerical concepts (Schwartz et al., 1997). The first question assesses familiarity with the concept of probability, the second assesses ability to convert percentage (1%) to proportion (10 in 1000), and the third assesses the reverse calculation with conversion of a proportion (1 in 1000) to percentage (0.1%) (Schwartz et al., 1997). Participant score is based on the number of questions answered correctly with scores ranging from 0 (no correct answers) to 3 (all questions answered correctly).

An eight item 'expanded' numeracy questionnaire framed risk / probability questions within the context of health (Lipkus et al., 2001). These questions were developed to mimic the same or similar mathematical operations incorporated into the 3-question general numeracy instrument described above. Researchers concentrated on probabilities, proportions, and percentages because of their widespread use in educational risk communication materials, decision aids, and clinical risk conversations. Examples of probability questions contextualized within a healthcare setting include:

- 1. Which of the following numbers represents the biggest risk of getting disease?
- (a) 1 in 100, (b) 1 in 1000, (c) 1 in 10 (Answer = 1 in 10)
- 2. The chance of getting a viral infection is 0.0005, and out of 10,000 people, about how many of them are expected to get infected?

(Answer = 5)

Participant scoring possibilities range from 0 (no correct answers) to 8 (all correct answers).

Weiss et.al. (2005) developed a health literacy screening test incorporating an assessment of prose health literacy and numeracy skills (Weiss, Mays, Martz, Castro,

DeWalt, Pignone, Mockbee, & Hale, 2005). The Newest Vital Sign (NVS) is an instrument consisting of six assessment questions contextualized to information on an ice cream nutrition label (visual prop) (see Appendix B). Sample questions include: (1) If you eat the entire container [of ice cream], how many calories will you eat? [Only correct response is 1,000 calories], and (2) If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving? [Only correct answer is 10%]. Participants score one point for each correct answer with a response range of 0-6. The average time for test administration is approximately 3 minutes for the English version and slightly longer (approximately 3.5 minutes) for a Spanish version. Relative to the TOFHLA, the NSV-English showed that a score less than 2 had a sensitivity of 72% and specificity of 87% for predicting limited literacy skill (TOFHLA score <75). Both instruments revealed good psychometric properties with good internal consistency (Chronbach's  $\alpha = 0.76$  English; 0.69 Spanish), and good face and criterion validity.

Three other instruments have been used to evaluate numeracy, with varying success in the healthcare sector (Lynch, 1995). These are referred to as 'cognitive functioning' tests or tests of academic achievement and include the Wide Range Academic Test – 3 (WRAT-3), the Kaufman Functional Academic Skills Test (K-FAST), and the Mini-Battery of Achievement (MBA) test. WRAT-3 has been cited as one of the most frequently used instruments, and is described as a screening instrument; it measures word recognition, spelling, and mathematical skills (Flanagan, McGrew, Abramowitz, Lehner, Untiedt, Berger, & Armstrong, 1997). WRAT-3 is appropriate for use with individuals ranging from 5-74 years and takes 3 to 5 minutes to administer and score. The reading and spelling components evaluate word recognition skills. The arithmetic portion of the instrument examines respondents' ability in counting, recognition of number symbols, and solving oral and computational problems. The

demanding reading level of the WRAT-3 is not appropriate to individuals with basic to low reading ability (Davis et al., 1998) and the test for validity is limited (Lynch, 1995).

The K-FAST is designed to measure academic skill within an everyday context (Flanagan et al., 1997). The reading component consists of items intended to assess respondents' recognition and comprehension of familiar text such as recipes, newspaper ads, and drug labels, (Flanagan et al., 1997; Lynch, 1995). The numeracy component features activities such as reading charts, graphs, and maps, understanding time, spending and budgeting money in an effort to assess respondents' ability to apply mathematical concepts to everyday life (Flanagan et al., 1997; Lynch, 1995). The K-FAST takes approximately 15-25 minutes to complete and is used for individuals 15 to 85 years. Measures of internal reliability (0.94) and test – re-test reliability (0.91) were high for this instrument. Concurrent validity has been demonstrated within the academic literature (Flanagan et al., 1997).

Finally, the MBA assesses skills for reading, writing, mathematics, and factual knowledge (Flanagan et al., 1997). There is a word and letter identification component, a test of vocabulary, written exercises and a proofreading process that entails the writing domain of the assessment. The mathematics domain assesses respondents' ability to manipulate numbers (addition, subtraction, multiplication, division, geometry, trigonometry, and calculus), to solve math problems, and to demonstrate knowledge of mathematical concepts and vocabulary. The instrument includes a single test of factual knowledge intended to gauge respondents' general knowledge in social studies, science, and the humanities. The reading, writing, and mathematical scores together form a basic skills cluster composite score (Flanagan et al., 1997). The MBA takes 25-30 minutes to complete and reportedly the test is generalizable for the screening of academic skills of individuals 4 – 95 years (Flanagan et al., 1997).

Flanagan and colleagues (1997) compared the K-FAST, MBA, and the WRAT-3 for concurrent validity. The math component across the three instruments was comparable. The K-FAST was found to be most appropriate in determining whether individuals have the academic skills necessary to function effectively within an everyday context. The construct validity of the WRAT-3 and the K-FAST was assessed for medically diverse populations (head injuries and stroke patients, psychiatric and substance abuse patients, HIV, multiple sclerosis, muscular dystrophy patients, individuals with ADD) (Klimczak, Bradford, Burright, & Donovick, 2000). However, the K-FAST was less intimidating to respondents who lack confidence in academic skill as opposed to the academic 'test taking' perspective of the WRAT-3. Beyond the comfort of familiarity, the K-FAST was notably faster to administer (≈10 minutes faster) than the WRAT-3.

To date, none of the academic achievement tools (i.e., K-FAST), the 3-question general context numeracy assessment, or the 8-question health context numeracy scale have been included in any comparative studies with the TOFHLA or the S-TOFHLA. Although the academic achievement instruments may be suitable to assess functional health literacy, a comparative analysis would be required to determine if this is so. Research is needed to determine which instrument is most effective in demonstrating individual understanding of information contextualized to health.

Newly developed, the Medical Data Interpretation Test is an 18 item assessment of patients' medical data interpretation skills (Schwartz, Woloshin, & Welch, 2005). The multiple choice test items were modeled on the quantitative and document literacy assessment of the U.S. National Adult Literacy Survey and assess patients' ability to make sense of and compare medical statistics about disease risk and risk reduction (Schwartz et al., 2005). Correct responses to the test items were counted and transformed to scores ranging from 0-100. The test revealed good internal

consistency (Cronbach's  $\alpha=0.71$ ), good test-retest reliability, high content validity assessed by 15 physicians, and good construct validity. Beyond establishing the psychometric properties of the test with community dwelling and clinic outpatient participants (Schwartz et al., 2005), there are no published studies incorporating the use of this newly developed instrument. Schwartz et al. (2005) suggest that potential applications might include the assessment of patient readiness for dealing with medical statistics and appraisal of patient readiness for participation within the shared decision-making health encounter.

## 1.8 Framework for Risk Comprehension

The National Cancer Institute (NCI) states that health communication contributes to: increased knowledge and awareness of a health issue, problem, or solution; influencing perceptions, beliefs, and attitudes with the potential to change social norms; bringing about action; modeling healthy skills and reinforce healthy behaviours and attitudes; showing the benefit of behavior change; and refuting myths and misconceptions (NCI, 2001). As a specialized form of health communication, "cancer risk communication must traverse a great conceptual distance - from probabilities, based on mathematics derived from populations, to the calculation of individual risk, and then to the accurate perception of personal risk by individuals.... A real potential exists to improve health in the correct understanding of personal risk. It can increase knowledge, facilitate decision-making, motivate new behaviours, and change existing behaviours" (Rimer & Glassman, 1999). Key objectives for determining and communicating cancer risk are: (1) the need to change or modify behaviour and, (2) the ability to facilitate knowledgeable decision-making (Julian-Reynier, Welkenhuysen, Hagoel, Decruyenarere, & Hopwood, 2003). Risk

comprehension, critical to the provider – consumer encounter, is particularly complex (Weinstein, 1999).

To address these objectives, the practice of patient participation in planning, decision-making and implementing therapeutic strategies is strongly advocated (Adelsward & Sachs, 1996; Bogardus, Holmboe, & Jekel, 1999; Hanoch & Pachur, 2004; Littenberg, 1994; Mazur & Hickman, 1991; Parker et al., 1995; Sutherland, Lockwood, Tritchler, Sem, Brooks, & Till, 1991; Walter & Covinsky, 2001). "Shared decision-making is seen as a mechanism to decrease the informational and power asymmetry between doctors and patients by increasing patients' information, sense of autonomy and /or control over treatment decisions that affect their wellbeing" (Charles, Gafni, & Whelan, 1997, p. 682). Positioned midway on a continuum between the paternalistic (physician as decision-maker) and informed decision-making models (consumer as decision-maker), the shared model of decision-making endorses a collaborative process introducing interventions that not only provide consumers with information but also with critical analysis strategies (Charles et al., 1997). The need for a shared-decision making arrangement is most compelling in cancer where numerous treatment options exist, and where different benefits and risks must be evaluated under conditions of uncertainty (Charles, Whelan, & Gafni, 1999). The necessary criteria for shared-decision making within healthcare include:

(1) Participation of at least, the physician and consumer. Often treatment decision-making within cancer is a process involving several physicians and many medical encounters. Especially in the case of serious illness, consumer advocates (family members, friends, etc.) enter the decision-making process and take on a variety of roles (information gatherer, advisor, negotiator, caretaker).

- (2) Agreement and endorsement of both parties regarding the decision. This does not always mean that the chosen treatment is believed to be the best available but that it is the preferred treatment.
- (3) Information sharing as prerequisite to the process of shared decision-making. Physician sharing of information is a core component of the decision-making process although consumers are increasingly introducing information sought from outside the clinical encounter.
- (4) Both physician and consumer participate in the process of decision-making. The physician role includes sharing information on options, risks, and benefits of possible treatment and ensuring consumer comprehension of the information. The consumer role includes the "responsibility for disclosing preferences, asking questions, weighing and evaluating treatment alternatives and formulating a treatment preference" (Charles et al., 1997). As a component of decision-making, risk comprehension involves an understanding of and the ability to judge the severity of potential harm. Consumer understanding of the probability of harm is partly dependent on the comprehension of numeric estimates of risk (Weinstein, 1999).

There is a growing interest in the influence of numeric literacy on the comprehension and communication of cancer risk. Existing evidence suggests that individuals with low numeric skill are less able to accurately assess and personalize health risk. For example, Schwartz et al. (1997) found that women (27-88 years) with low numeric skill struggled to correctly interpret risk reduction data when asked to estimate their risk of death from breast cancer with and without screening mammography. Even with available data, (e.g., relative risk reduction, absolute risk reduction) women overestimated the effectiveness of mammography screening. In fact, the relationship between estimate accuracy and numeracy persisted even after adjusting

for age, income, level of education and framing of the risk information. Similarly, women who scored low in numeracy were more likely to overestimate their lifetime breast cancer risk; this finding suggests an important link between numeracy skills and the ability to accurately interpret risk estimates (Davids et al., 2004). Poor numeric skill by incident head and neck cancer patients negatively influenced self-reported quality of life, with innumerate patients' responses to utility measures of questionable validity. For those with strong numeracy skills "...quantitative messages may convey information concisely and with great precision. However ...for many persons, quantitative expressions may have no meaning or may represent useless and potentially confusing information" (Schwartz, et al., 1997, p.970).

The relationship between numeracy and risk comprehension was further studied by Weinstein (2004). Estimates of colon cancer risk were greatly overestimated, with adults (e.g., average age 55 years, culturally diverse, outpatient clinic participants) scoring low in numeracy more likely to give unrealistically high estimates of risk. Yet, regardless of numeric skill, when presented with personalized risk information, participants' initial estimates of risk remained relatively unchanged. One explanation included an inadequate assessment of numeracy using only 2 rather than 3 or 8 numeracy assessment questions. Moreover, participants were reportedly doubtful of the personalized feedback regarding cancer risk and persisted in overestimating personal risk estimates. In addition, numeracy skill appears to mediate feelings of trust and comfort in risk communication exchanges between physicians and patients (Gurmankin, Baron, & Armstrong, 2004). Low numerate individuals had greater confidence in risk information presented by physicians in a non-numeric format (i.e., qualitative expressions of risk; high or low risk) whereas higher numerate individuals expressed greater trust in information articulated numerically. This has important implications for

tailoring risk communication to patient numeracy skill, and underscores the need for effective numeracy assessment strategies for use within clinical settings.

Finally, Hopwood (2000) found that consumer concept of risk is rarely investigated. "...Research has largely assessed women's risk knowledge in the same terms as used by health professionals in genetics consultations, assuming that the lay construction of risk is comparable with objective estimates by health professionals. There has been little qualitative research focused on their meaning of risk, and it may be difficult to know what exactly is being considered when women formulate their personal risks" (Hopwood, 2000, p.388).

All of these studies used either a 3-question or 2-question general numeracy instrument to assess participant numeracy. Risk comprehension using a combined measure of reading comprehension and numeracy was not evaluated (e.g., a test of functional health literacy such as the TOFHLA or S-TOFHLA). Moreover, Steen (1999) argued that accuracy in response to mathematical calculations does not constitute a true measure of numeracy and, more importantly, does not guarantee accurate comprehension of the nature of risk. Konold (1993) cautioned that assessment limited to appraisal of correct performance on single answer response questions (i.e., multiple choice response to mathematical questions) is an inadequate reflection of individuals' view of probabilistic or statistical reasoning.

#### 1.9 Summary of the Literature

Health literacy skills are compulsory for effective functioning within contemporary healthcare (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999; Fuller et al., 2001; HRSDC, 2004). Yet, a substantial proportion of adults are limited in both general literacy and functional health literacy (prose and numeracy) skills (Baker et al., 2000; Baker et al., 2004; Baker et al., 1998;

Fuller et al., 2001; Gazmararian, et al., 1999; Health Canada, 2003; HRSDC, 2004; Lipkus et al., 2001; Schwartz, et al., 1997; Schwartz, McDowell & Yueh, 2004; Sheridan, et al., 2003; Williams et al., 1995). An investigation of health numeracy determined that poor numeracy skill compromises the validity of numerically based quality of life assessments (Woloshin et al., 2001). Numeracy skill has been associated with individual ability to interpret superior treatment benefits of two different medications (Sheridan et al., 2003). Numeracy skill was also linked to accurate perception of breast cancer risk (Davids et al., 2004). Those with limited numeracy skill tended to overestimate their lifetime risk of breast cancer suggestive of a link between numeracy level and accurate risk interpretation (Davids et al., 2004). These observations raise important questions about individual ability to accurately interpret and personalize risk information.

None of the studies investigating the relationship between numeracy and cancer risk comprehension assessed prose health literacy. The tools in these studies assessed numeracy using either a general context or a health context assessment of numeracy. Steen (1999) states that numeracy is revealed through the appropriate use of numeric skills in a wide variety of contexts (Steen, 1999), whereas others suggest that numeric skill is dependent on familiarity of the situation or context (Health Canada, 2003; IOM, 2004). Even with evidence of an association between numeracy and risk comprehension, numeracy skill contextualized within healthcare maybe a poor proxy of risk comprehension ability (Lipkus et al., 2001). Despite the positive correlation between formal education and literacy (prose / numeracy) skill, a substantial proportion of adults do not fit this pattern. In fact, almost 25% of those with higher education levels have low literacy functioning (Statistics Canada, 2005a). Attendance at school does not directly translate into well-developed literacy skill. Differences in acquisition and maintenance of literacy skills may also explain the observed inconsistency.

Practice is required to maintain literacy skills (Statistics Canada, 2005a). High workplace literacy demands or leisure literacy pursuits also contribute to the maintenance of literacy skill. Similarly the relationship between health literacy and formal education is not always consistent (Baker et al., 1999; Williams et al., 1995). Thus, the main research gaps arising from the literature include: (1) conceptual clarification regarding health literacy and health numeracy, (2) issues regarding measurement of health literacy / numeracy skill, and (3) determination of factors influential to the development and maintenance of health numeracy and risk comprehension skill.

# 1.9.1 Study Components and Rationale

The main objectives of this study were to explore: (1) the relationship between assessment instruments measuring numeric literacy and functional health literacy, (2) the relationships between formal education, math anxiety as a measure of practice, prose functional health literacy, and health numeracy skill, and lastly to evaluate (3) the relationships between formal education, math anxiety as a measure of practice, familiarity of context, prose functional health literacy, and health numeracy skill and risk comprehension.

This thesis describes two research studies on health context numeracy and cancer risk comprehension skills of community dwelling older Canadians. Study 1 (Chapter 2) describes health context numeracy skills of older adults and was designed to explore the variability in participant numeracy skills, using the explanatory variables of prose health literacy, level of attained education, and math anxiety. The rationale comes from an increased prevalence of chronic disease (i.e., colorectal cancer), requiring a disease management healthcare perspective that incorporates a participatory model of care (Charles et al., 1999). Meaningful patient participation is made possible

through increased access to and comprehension of health information. Healthcare discussions often turn to talk of risk, thus assigning quantitative information to priority status within the healthcare encounter and at the same time, highlighting the need for adequate health numeracy skills (Bottorff, Ratner, Johnson, Lovato, & Joab, 1996; Golbeck et al., 2005b). However, within the research literature, health literacy is largely portrayed as a reading skill with numeracy attracting less attention (Golbeck et al., 2005b). Study 1 describes the health numeracy skill of community dwelling older adults and considers how prose health literacy, math anxiety, and level of education influence participant health context numeracy scores.

Chapter 3 (Study 2) evaluated the contribution of prose health literacy, numeracy skill, math anxiety, level of attained education, and context of information to variation in older adults' risk comprehension skill. As a component of decision-making, risk comprehension involves an understanding of and the ability to judge the severity of potential harm. Consumer understanding of the probability of harm is partially dependent on the comprehension of numeric estimates of risk (Weinstein, 1999). The rationale for Study 2 follows from Study 1. The comprehension of risk contributes to improved healthcare by increasing healthcare knowledge, facilitating decision-making, motivating new behaviours, and changing existing behaviours (Hay, Shuk, Cruz, & Ostroff, 2005; Julian-Reynier et al., 2003; Weinstein, 1999). The need for risk comprehension is most compelling in cancer care situations where numerous treatment options exist and where different benefits and risks must be evaluated under conditions of uncertainty (Weinstein, 1999). Figure 1 shows the relationship between the two main study components.

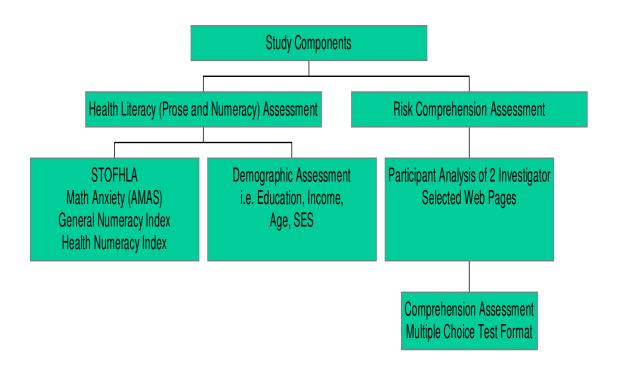


Figure 1: Study components on the assessment of health literacy (prose and numeracy) and risk comprehension of web-based cancer information

#### Chapter 2:

## **Assessing Health Numeracy Among Community Dwelling Older Adults**

#### 2.1 Abstract

Quantitative information occupies a central role within healthcare decision-making. Despite this, numeracy has attracted little research attention. Therefore the purpose of this study was to: (1) describe the health numeracy skill of a non-clinical, Canadian community based senior population and (2) determine the relationship between health numeracy skill and prose health literacy, education, and math anxiety in this population. A convenience sample of 140 men and women, 50+ years, completed a questionnaire assessing demographic details, math anxiety, functional health literacy (STOFHLA), general context numeracy, and health context numeracy skills. Most participants (91%) had adequate functional health literacy (prose and numeracy) as measured by the STOFHLA, poorer general context numeracy skill, higher health context numeracy skill, and moderate math anxiety. Approximately 36% of the variation in general context numeracy scores and 26 % of the variation in health context numeracy scores were explained by prose health literacy skill (STOFHLA), math anxiety, and attained education. This research offers an initial assessment of health numeracy skills as measured by three existing numeracy scales among a group of independently functioning older Canadian adults. This work highlights the need for clarification of the numeracy concept and refinement of health numeracy assessment instruments. Moreover, identifying patients' numeracy strengths and weaknesses will enable the development of focused numeracy interventions and may contribute to moving individuals further along the continuum of health literacy proficiency.

## 2.2 Research Objectives

**Objective 1:** Using the Test of Functional Health Literacy for Adults (S-TOFHLA), and two probability-based numeracy instruments, the first objective was to determine the health literacy and numeracy skills of adult participants.

**Objective 2:** The second objective was to assess the relationship between participants' skill in functional health literacy and numeracy using the three assessment instruments: the Test of Functional Health Literacy for Adults (S-TOFHLA), and two probability-based numeracy instruments.

**Objective 3:** The third objective was to determine how much of the variability in participant numeracy skill is explained by the skill in prose literacy, formal education, and math anxiety.

#### 2.3 Hypotheses

**Hypothesis 1:** Participant skill in functional health literacy and numeracy will demonstrate a continuum of ability revealing a wide range of skill levels.

This hypothesis is based on results of the IALS/IALLS (HRSDC, 2004; Statistics Canada, 2005a, 2005c), which indicates that the contemporary model of literacy reflects a continuum of expertise ranging from limited to highly skilled. This hypothesis is also reflected in the published assessments of functional health literacy and numeracy within a healthcare setting (Baker et al., 2002; Baker et al., 1999; Lipkus et al., 2001; Schwartz, et al., 1997).

**Hypothesis 2:** Participant skill on the STOFHLA and the 8-item health based numeracy instrument will be greater than on the 3-question general numeracy instrument.

This hypothesis is based on the understanding that numeracy is an applied skill and that the tasks assessed within the test for functional health literacy and the 8-question instrument are applied to realistic healthcare episodes. In contrast, the 3-question instrument requires the participant to draw on theoretical mathematical concepts to respond. In essence, the 3-question instrument is least representative of the concept of health numeracy.

**Hypothesis 3a:** As participant scores in prose literacy (reading component of functional health literacy test) improve, numeracy scores will increase.

This hypothesis is based on the published literature indicating that numeracy success is dependent, in part, on one's ability to identify and comprehend numeric information embedded within text (Dingwall, 2000).

**Hypothesis 3b:** Assessed participant numeracy scores will be inversely related to mathematics anxiety scores.

This hypothesis is based on the following key findings from the literature. Math confidence, as a function of opportunity for practice, contributes to increased numeracy. Key findings from the IALS indicate that numeracy practice within activities of daily life improves numeric capacity (HRSDC, 2004). Mathematics anxiety will be used as a proxy measure of skill practice. Poor numeracy scores will be resultant of the underlying assumption that those with high math anxiety scores will avoid situations that involve the use of numbers, will be less inclined to seek out opportunities to utilize mathematical skills, and will be assumed to have less practice and opportunity for skill utilization (Hopko, Mahadevan, Bare, & Hunt, 2003a; Hopko, McNeil, Lejuez, Ashcraft, Eifert, & Riel, 2003b).

**Hypothesis 3c:** With increased levels of attained education, numeracy scores will also increase. Skill utilization is a significant component of numeracy skill development. Math anxiety is a moderating variable in the development of participant numeracy skill. This hypothesis is based on the following observations.

moderating variable influencing the relation between the explanatory variables of level of education and health numeracy skill, the response variable of interest (Baron et.al., 1986).

45

<sup>&</sup>lt;sup>1</sup> A moderator is a qualitative (e.g., sex, race, class) or quantitative (e.g., level of reward) variable that affects the direction and/or strength of the relation between an explanatory or predictor variable and a response or criterion variable. In this case, the math anxiety is the moderating variable influencing the relation between the explanatory variables of level of

First, numeracy skills are introduced and developed within the formal education system but these skills are only maintained and strengthened through practice (Dingwall, 2000; HRSDC, 2004; Steen, 2001b). Most Canadians conform to the model that portrays increased numeracy with increased levels of formal education (HRSDC, 2004; Statistics Canada, 2005a, 2005c). Yet, approximately one quarter of Canadian adults reveal low functioning numeracy skill with higher levels of formal education or greater numeracy skill with low educational achievement (Statistics Canada, 2005a, 2005c). Similar findings with respect to functional health literacy have also been demonstrated (Baker et al., 1999). Math anxiety is introduced as a proxy measure for numeracy skill utilization and moderates the relationship between level of attained education and numeracy proficiency. This is based on the knowledge that those with high math anxiety are likely to avoid situations involving numbers and would be less likely to develop adequate numeracy skills.

Permission has been granted by the Journal of Health Communication to include the work presented in the remainder of this chapter (01/17/2007). This work has been accepted for publication as:

Donelle, L., Hoffman-Goetz, L., Arocha, J.F (in press) Assessing Health Numeracy Among Community Dwelling Older Adults. *Journal of Health Communication* 

**Assessing Health Numeracy Among Community Dwelling Older Adults** 

## 2.4 Introduction

Both a contributor to poor health and an intervention for improved health, (Health Canada, 2003; IOM, 2004; Nutbeam, 2000), health literacy is defined by the Institute of Medicine as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Nielsen-Bohlman, Panzer & Kindig, 2004, p. 4). Recent

adult literacy survey (IALS, ALL) results indicate that more than 50 % of older adults (45-65 years) are at the lowest category of general prose and general numeric literacy. The absence of health literacy estimates for Canadian adults, including health numeracy data for older Canadians (50-90 years), is striking (HRSDC, 2004; Statistics Canada, 2005c).

Contemporary healthcare is marked by the prevalence of chronic disease, which has necessitated a healthcare model that aligns with disease management and illness prevention more than a curative paradigm. This alignment calls for increased patient participation in healthcare planning (Charles, Whelan, & Gafni, 1999). The resultant patient-provider discourse often turns to talk of risk, thus assigning quantitative information to priority status within the healthcare encounter (Bottorff, Ratner, Johnson, Lovato, & Joab, 1996; Golbeck, Ahlers-Schmidt, Paschal, & Dismuke, 2005b). However, health literacy is largely portrayed as a reading comprehension skill with numeracy attracting little research attention (Golbeck et al., 2005b). In the United States, low health literacy is associated with people of African American heritage, older individuals, those with little attained education and low income (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005). The reporting of health literacy without disaggregating prose from numeracy obscures health numeracy skill. Consequently, it is difficult to determine whether the associations of prose literacy with age, education, and income also characterize health numeracy skill.

Health numeracy has been defined as the "degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions" (Golbeck et al., 2005b, p. 375). To date, assessment of numeracy skill reveals limited competency. Small clinical studies indicate that 26 to 71% of individuals have inadequate health numeracy skill (Weiss et al., 2005; Davids,

Schapira, McAuliffe, & Nattinger, 2004; Lipkus et al., 2001; Sheridan, Pignone, & Lewis, 2003; Sheridan & Pignone, 2002; Woloshin, Schwartz, Moncur, Gabriel, & Tosteson, 2001). Identified as a practice-driven competence, numeracy skill is rarely reinforced within the home or school environment (Dingwall, 2000; Steen, 1990). Moreover, people who experience math anxiety avoid situations involving numbers and are less likely to develop adequate numeracy skill (Hopko, 2003).

The purpose of the present study was to: (1) describe the health prose and numeracy skill of a non-clinical community based population of older adults using the Test of Functional Health Literacy for Adults (STOFHLA), and three-item general context and eight-item health context numeracy instruments, (2) assess older adults' numeracy skill as measured by the STOFHLA relative to numeracy skill measured by the three-item general context numeracy tool and the eight-item health context numeracy instrument, and (3) describe the relationship between health numeracy skill and prose health literacy, education, and math anxiety. We hypothesized that (1) older Canadians' skill in functional health literacy as measured by the STOFHLA and numeracy scales would show a continuum of ability revealing a wide range of skill levels, (2) skill on the STOFHLA and the eight-item health context numeracy instrument would be greater than on the three-question general context numeracy scale, (3) numeracy scores would increase with increased levels of education and of prose health literacy scores as measured by the STOFHLA, and (4) older adults' numeracy scores would be inversely related to mathematics anxiety scores.

#### 2.5 Methods

The research was introduced as a project aimed at understanding participant comprehension of health information regarding cancer. Individuals were asked to commit to a single, 90-minute interview that took place at regional libraries and

community senior centers. Volunteers were offered a small stipend of \$40.00 for participating.

## 2.5.1 Recruitment of Participants

A convenience sample of 140 adult men and women was recruited from the communities of Kitchener, Waterloo, Cambridge, and Guelph in southern Ontario during 2005. Study inclusion required that participants be able to: (1) read and comprehend information in English, (2) live independently within the community and (3) be 50 years of age or older. Request for participation was publicized at the Kitchener Public Library, community senior centres (Breithaupt Centre, Fairview Mennonite Apartments, Ted Wake Lounge, Allan Reuter Centre, Rockway Senior Centre) and through advertisements in three local newspapers. Recruitment posters (see Appendix G) were placed on general information bulletin boards in all locations. The study was advertised as an investigation of older adult understanding of cancer information. Activity coordinators from each community senior centre acted as a liaison between the researcher and the community centre. Thirty information sessions were conducted at the local library and 110 information sessions were completed at the various community centres.

Participants completed a demographic questionnaire (refer to Appendix H). Math anxiety was assessed using the Abbreviated Math Anxiety Scale (AMAS) (refer to Appendix L) (Hopko et al., 2003a). Measures of health literacy (prose and numeracy) were obtained by the shortened-Test of Functional Health Literacy for Adults (STOFHLA) (Baker et al., 1999) (refer to Appendix I) along with a three-item general context (refer to Appendix J) and eight-item health context (refer to Appendix K) numeracy questionnaires (Lipkus et al., 2001; Schwartz et al., 1997).

## 2.5.2 Functional Health Literacy

The STOFHLA consists of 36 prose and four numeracy questions. Numeracy questions ask respondents to calculate medication schedules (i.e., instructions indicate one tablet by mouth every 6 hours as needed and the respondent is asked to calculate the time of the next dose if the first dose of medication is taken at 7:00am) and to identify number patterns (i.e., to determine whether a blood sugar value falls within the normal range. The normal range is given). Correct responses scored one point each. The total prose score was multiplied by 2 (x36) and the total numeracy score was multiplied by 7 (x 4). The sum of the two sections provides a measure of the functional health literacy ranging from 0-100. Scores from 0-55 indicate inadequate functional health literacy, scores from 56-66 indicate marginal health literacy and scores between 67-100 indicate adequate functional health literacy skill. The STOFHLA shows adequate internal consistency (Cronbach's  $\alpha = 0.68$ ) for the numeracy items and good internal consistency (Cronbach's  $\alpha = 0.97$ ) for reading comprehension. The correlation was reasonable between the STOFHLA and the REALM at 0.80 (Baker et al., 1999).

#### 2.5.3 Three-Item General-Context Numeracy Assessment

A three-question general context protocol was used to assess numeracy skill (Lipkus et al., 2001; Schwartz et al, 1997; Sheridan et al., 2003). Participants' scores were based on the number of questions answered correctly with a response range from 0-3. Three questions assessed participant familiarity with the concept of probability, their ability to convert percentage (1%) to proportion (10 in 1000), and their ability to convert proportion (1 in 1000) to percentage (0.1%) (Schwartz et al, 1997). This instrument has modest internal consistency with Cronbach's  $\alpha$  scores of 0.63, 0.61, 0.57 from three separate sample populations (Lipkus et al., 2001). Scores from this index

are consistent with assessed National Adult Literacy Survey (NALS) quantitative literacy scores (NCES, 2005) and with numeracy questions specific to anticoagulation control (Estrada, Martin-Hryniewics, Peek, Collins, & Byrd, 2004). Details of this instrument are given in Appendix M.

# 2.5.4 Eight-Item Health-Context Numeracy Assessment

An eight-item 'expanded' numeracy questionnaire framed questions within the context of health (Lipkus et al., 2001). Similar to the three-item general-context numeracy instrument, this index measures participants' ability to differentiate magnitude of risk (i.e., Which of the following numbers represents the biggest risk of getting a disease? 1%, 10%, 5%), and to perform simple mathematical operations (i.e., If the chance of getting a disease is 10%, how many people would be expected to get the disease? Out of 100; Out of 1000). Participants scored one point for each correct response with scores ranging from 0 (no correct answers) to 8 (all correct answers). Internal consistency was reasonable with computed alpha scores of 0.74, 0.70, and 0.75 for three separate samples totaling 463 participants (Lipkus et al., 2001). Details about this instrument are available in Appendix K.

# 2.5.5 The Abbreviated Math Anxiety Scale (AMAS)

The AMAS is a nine-item scale with strong internal consistency (Cronbach's  $\alpha$  = .90) and test-retest reliability (r = .85) (Hopko et al., 2003a). Test items are formatted using a Likert type scale with responses ranging from 1 (low anxiety) to 5 (high anxiety) with a maximum score of 45. The test requires participants to indicate their anxiety level, using a scale of 1 to 5, in situations where they would "have to use the tables in the back of a math book", or "Listen to another student explain a math formula" (Hopko et al., 2003a). This test is described in Appendix L.

## 2.5.6 Statistical Analysis

All analyses were conducted with SPSS, Version 14.0 (SPSS, 2005). Data were initially reviewed for accuracy of data input. Frequency distributions for continuous variables were reviewed to determine normal distribution (histograms, box plots, stem and leaf diagrams). Descriptive statistics for participant demographics (i.e. age, income, education), and participant scores of STOFHLA health literacy, health context numeracy, and general context numeracy skill, and math anxiety were summarized. Frequency distributions were completed for STOFHLA numeracy scores, health context numeracy scores, and general context numeracy scores. Non-parametric analyses were used for categorical data and for comparisons between groups. Correlation coefficients were assessed using Spearman R non-parametric correlation. Fishers exact chi square analyses assessed relationships between categorical variables (i.e. age/ self rated reading skill/ self rated statistical skill and general context numeracy/ STOFHLA numeracy scores). Gender differences between variables were assessed using the Mann-Whitney U, non-parametric measure.

Health context numeracy (eight-item scale) was the response variable for multiple regression analysis. The general context numeracy (three-item scale) skill (0-1 scores = 0, 2-3 scores =1) constituted the response variable in logistic regression analyses<sup>2</sup>. There were inadequate participant numbers to maintain the statistical integrity required for ordinal logistic analysis, therefore the general-context numeracy data were transformed from a four category scale into a dichotomy of numeracy scores (0-1 scores = 0, 2-3 scores =1) appropriate for logistic regression analysis (E. Harvey, March 6, 2006).

\_

<sup>&</sup>lt;sup>2</sup> Inadequate participant numbers to maintain the statistical integrity prevented the application of ordinal logistic analysis; therefore, the general-context numeracy data was transformed from a four category scale into a dichotomy of numeracy scores (0-1 scores = 0, 2-3 scores = 1) appropriate for logistic regression analysis.

Prose health literacy as measured by the STOFHLA, level of education, and math anxiety were chosen *a priori* for regression modeling. Subsequent modeling included: age, self-reported statistical comprehension, self-reported reading frequency, and income as explanatory variables. Statistical consultation (E. Harvey) recommended that gender be included (controlled) in all regression equations regardless of statistical significance. The unequal numbers of females (n = 103) to males (n = 37) served as rationale for this decision. Residual plots were assessed to confirm the integrity of regression model assumptions (residuals are independent, normally distributed, and have a constant variance). A P value of 0.05 was used to indicate statistical significance.

#### 2.6 Results

Demographic Characteristics of Participants

Table 2 shows the demographic profile of the 140 participants in the study. Participants ranged in age from 50-80+ years with almost two-thirds (65%) of participants between 50-69 years. There were more women (n= 103, 73.6 %) than men (n= 37 males, 26.4%) enrolled. The majority of participants were married (48.6%), retired (63.6%), well educated (52.9% college or university degree), and at a lower annual income level (< \$35,000; 56.5%).

**Table 2 Description of Participant Demographics** 

Variable		N	%
Participants		140	100
•	Males	37	26.4
	Females	103	73.6
Age	50-59	47	33.6
8	60-69	44	31.4
	70-79	37	26.4
	80+	12	8.6
Marital Status	Single	10	7.1
	Married	68	48.6
	Separated	7	5
	Divorced	24	17.1
	Widowed	28	20
	Other	3	2.1
Employment	Full-time	12	8.6
	Part-time	20	14.3
	Retired	89	63.6
	Not employed	18	12.9
	Other	1	0.7
Income	Less than 14,999	25	17.9
	15,000-34,999	54	38.6
	35,000-54,999	39	27.9
	55,000-74,999	13	9.3
	75,000-99,999	4	2.9
	100,000+	1	0.7
	Missing	4	2.9
Education	≤ Gr. 8	9	6.4
	Some High School	21	15.0
	High School diploma	24	17.1
	College /University	74	52.8
	degree	11	7.9
	Graduate degree	1	0.7
	Missing		
Born in Canada	Yes	104	74.3
	No	34	24.3
Preferred	English	135	96.4
language	French	1	0.7
	Other	2	1.4
	Missing	2	1.4
Perceived	Poor	1	0.7
Reading Skill	Fair	2	1.4
_	Good	9	6.4
	Very Good	46	32.9
	Excellent	82	58.6

D 1	T 41 41		C 4
Read a	Less than once a month	9	6.4
Newspaper in	At least once a month	11	7.9
last 12 months	At least 3 times a week	36	25.7
	Daily	83	59.3
	Missing	1	0.7
Read a	1 to 4 times per year	5	3.6
magazine in	5 or more times a year	11	7.9
last 12 months	but not every month		
	At least once a month	46	32.9
	At least once a week	77	55.0
	Missing	1	0.7
Read a book in	At least one a year	12	8.6
last 12 month	At least one every 6	9	6.4
	months	25	17.9
	At least one every 3	46	32.9
	months	47	33.6
	At least one every	1	0.7
	month		
	At least one a week		
	Missing		
Perceived	Poor	1	0.7
Number /	Fair	9	6.4
Statistical	Good	50	35.7
Comprehension	Very Good	54	38.6
•	Excellent	26	18.6

# 2.6.1 Literacy and Numeracy Profiles of Participants

There was a range of functional health literacy skills (Table 3). The mean STOFHLA score (36 prose questions, 4 numeracy questions) was 89.7/100 (95% CI = 87.47, 91.93;  $\alpha$  = .92). The mean prose score was 63.5 (95% CI = 61.54, 65.45) out of a possible 72-point total. Most participants (n= 110; 78.6%) achieved a perfect score on the numeracy component of the STOFHLA. A score between 67 to 100 points on the STOFHLA reflects adequate functional health literacy indicative of individuals able to read, understand and interpret most health material. Most older adults had 'adequate' functional health literacy skill (n= 127; 91%).

There was a range of numeracy skills: 55% of participants had either none or one answer correct on the three-item general context numeracy scale, whereas approximately 29% of participants had two correct answers and 16% answered all three

questions correctly. For the general numeracy context scores, the obtained  $\alpha$  reliability coefficient for the sample was 0.81. The majority of older adults had difficulty correctly comprehending the concept of probability, converting a percentage value to a proportion, and converting a proportion to a percentage within general context situations. The mean score for the eight-item health context numeracy scale was 5.9 (95% CI = 5.54, 6.20;  $\alpha$  = .73) out of a maximum of score of 8 (mean percentage score = 73.75%). The majority of older adults in this study were able to properly assess magnitude of risk and to correctly respond to the health-based calculations of probabilities, proportions, and percentages. Lipkus et al. (2001) reported that 15 – 21% of respondents age 40 – 73 years correctly answered all three general context numeracy questions; between 29 and 34% of participants correctly answered all eight items of the health context numeracy scale. In the current study, 16% and 24% of participants, age 50-90 years, achieved a perfect score on the three-item general context and eight-item health context numeracy indices, respectively.

Nonparametric correlations were used to determine the strength of association between the three measurement scales (see Table 4). The eight-item health context numeracy scale was modestly associated with the three-item general context numeracy scale and the STOFHLA numeracy scale ( $r_s = 0.48$ , p< 0.01;  $r_s = 0.43$ , p< 0.01, respectively). The correlation between the three-item general context numeracy scores and STOFHLA numeracy scores was significant albeit more weakly associated ( $r_s = 0.23$ , p= 0.002).

Table 4 Non-parametric Correlations Between the Three Different Numeracy

Measures

Numeracy Test	Three Item Test	Eight Item Test	STOFHLA
Three Item Test	1.0	Rs =0.48*	Rs =0.23*
Eight Item Test		1.0	Rs =0.43*
STOFHLA			1.0

<sup>\*</sup>Significant at p < 0.01

Individuals expressed moderate math anxiety with a mean score of 23.8 (95% CI = 22.37, 25.21;  $\alpha$  = .91) from a maximum 45-point. Men (mean = 20.02, 95% CI = 17.71, 22.35) had less math anxiety than women (mean = 25.09, 95% CI = 23.41, 26.77) (see Table 3). Gender differences were found for a number of factors: men were better educated (Mann-Whitney U = 1446.5, p = 0.022), had higher health numeracy scores (Mann-Whitney U = 1315.5, p = 0.005), had higher general numeracy scores (Mann-Whitney U 1444.0, p = 0.024), and had lower math anxiety (Mann-Whitney U = 1136.50, p= 0.001). There were no significant differences between men and women on the combined STOFHLA prose and numeracy scores (Mann-Whitney U = 1797.5, p= 0.52), on the STOFHLA prose only score (Mann-Whitney U = 1878.5, p=0.89), or the STOFHLA numeracy only score (Mann-Whitney U = 1819.5, p=0.57).

General context numeracy skill declined with increased age ( $\chi^2$  = 18.06, df = 9, p=0.027). Increased age was inversely correlated with general context and health context numeracy skills ( $r_s$ = -0.308, p< 0.01 and  $r_s$ = -0.255, p=0.002, respectively). Participant STOFHLA composite scores for functional health literacy (inadequate, marginal, adequate skill level) decreased with increased age ( $\chi^2$  = 25.917, df = 6, p<0.01). Older age, especially for participants 80 years and older, was significantly

associated with decreased functional health literacy skills as measured by the STOHFLA. This age related decrease in functional health literacy, as measured by STOFHLA, was largely due to decreased prose skill ( $\chi^2 = 24.851$ , df = 6, p< 0.01). When the scores for the STOFHLA numeracy subcomponent were analyzed separately as a function of age, the relationship was not significant ( $\chi^2 = 9.313$ , df = 6, p= 0.108;  $r_s = -0.017$ , p=0.838).

Participant general context numeracy scores (three-item numeracy scale) were inversely related to math anxiety scores: as math anxiety increased, general context numeracy skill decreased ( $r_s$ = -0.379, p<0.01). The relationship between health context numeracy scores (eight-item numeracy scale) and math anxiety was somewhat weaker but also inversely correlated ( $r_s$ = -0.269, p= 0.001). As well, increases in attained education were associated with less math anxiety ( $r_s$ = -0.290, p= 0.001). However, math anxiety was not significantly correlated with STOFHLA numeracy skill ( $r_s$ = -0.11, p = 0.2).

Results confirm a positive relationship between formal (attained) education and numeracy skill. The three-item general context numeracy ( $r_s = 0.371$ , p<0.01), the eight-item health context numeracy ( $r_s = 0.346$ , p<0.01), and STOFHLA numeracy ( $r_s = 0.235$ , p=0.005) were modestly correlated with participant level of formal education.

Table 3 Prose Literacy, Numeracy Literacy, and Math Anxiety Assessment Total and Gender Specific Scores

Variable	Total Mean Scores (95% CI)	Male Mean Scores (95% CI)	Female Mean Score (95% CI)
Math Anxiety*	23.8	20.02	25.09
	(22.37, 25.21)	(23.41, 26.77)	(23.41, 26.77)
Health Numeracy*	5.9	6.8	5.63
	(5.54, 6.20)	(6.32, 7.27)	(5.23, 6.03)
S-TOFHLA total	89.7	92.11	89.47
	(87.47, 91.93)	(88.21, 96.02)	(86.82, 92.17)
S-TOFHLA prose	63.5	65.31	63.39
	(61.54, 65.45)	(61.82, 68.81)	(61.09, 65.7)
S-TOFHLA	26.20	26.8	26.08
numeracy	(25.58, 26.81)	(25.88, 27.72)	(25.3, 26.86)
Variable	Total %	Male %	Female %
S-TOFHLA level	Inadequate = 2	0	3
	Marginal = 7	8	7
	Adequate = 91	92	90
General Numeracy*	0-1 correct = 55	35	62
	2 correct = 29	43	23
	3 correct = 16	22	15

#### Note:

CI = confidence interval

# 2.6.2 Regression Modeling of General Context Numeracy and Health Context Numeracy

To assess the contributions of math anxiety, STOFHLA prose skill, and attained education on the three-item general context numeracy scores, a logistic regression was carried out with the scores dichotomized (0-1 scores = 0, 2-3 scores =1) for statistical integrity. Controlling for gender, approximately 36% of the variation in participant general numeracy scores was explained by STOFHLA prose skill, math anxiety, and level of education ( $\chi^2 = 43.178$ , df = 7, p<0.000; Nagelkerke R<sup>2</sup> = 0.363). Age,

<sup>\*</sup> Significant gender differences,  $p \le 0.05$ 

income, self-reported statistics / number comprehension, participant reading frequency, and prose literacy (STOFHLA) did not significantly contribute to the logistic model. The most parsimonious model included math anxiety and level of education as predictors of three-item general context numeracy skill ( $\chi^2$ = 43.037, df = 6, p< 0.01;  $\chi^2$ = 0.362) (see Table 5).

Multiple regression was used to evaluate variation in the eight-item health context numeracy scores. Controlling for gender, three factors (math anxiety, education, and prose literacy skill (STOFHLA) accounted for approximately 26% of the variance in participant eight-item health context numeracy skill (F= 11.385, f = 4, f= 0.258) (Table 5). Age, income, self-reported statistics comprehension, participant reading frequency, and math anxiety did not significantly contribute to the variation in health numeracy skills of participants. The most parsimonious model, accounting for approximately 27% of the variation in the eight-item health context numeracy scores, was explained by variation in STOFHLA prose scores and level of education (f= 16.491, f= 3, f=0.000, f= 0.268).

**Table 5. General Context Numeracy and Health Context Numeracy Regression Models** 

Explanatory Variable	General Context Numeracy Logistic Regression OR (95% CI)	Health Context Numeracy Multiple Regression β (95% CI)
Gender		-0.764 (-1.427, -0.101)**
Male	1.967 (0.766, 5.055)	
Female	Reference	
Education		0.519 (0.207, 0.830) ***
≤ grade 8	0.235 (0.026, 2.122)	
Some High School	0.112 (0.013, 0.939) *	
High School Diploma	0.355 (0.064, 1.964)	
College/University	0.970 (0.209, 4.515)	
Graduate Degree	Reference	
Math Anxiety	0.903 (0.853, 0.956) ***	-0.006 (-0.043, 0.032)
S-TOFHLA Prose	1.01 (0.966, 1.053)	0.048 (0.020, 0.077) ***

#### Note:

OR = Odds Ratio,  $\beta$  = Beta Co-efficient, CI = Confidence Interval

# 2.6.3 Moderated Effect of Formal Education by Math Anxiety on Health Context Numeracy Skill

Relationships between two variables can be enhanced or diminished by the presence or absence of moderator variables (Brewer, 2000). In the case of moderation, the relationship between the explanatory and response variable is influenced by a third variable or moderating factor (Brewer, 2000). For example, math anxiety (moderator variable) (M), as a proxy measure for numeracy skill utilization, is the proposed moderating variable influencing the relationship between level of formal education (explanatory variable) (X) and numeracy proficiency (response variable) (Y). This is

<sup>\*</sup> Relative to the reference group, significant at p < 0.05

<sup>\*\*</sup> Significant at p < 0.05

<sup>\*\*\*</sup>Significant at p < 0.01

based on the knowledge that those with high math anxiety are likely to avoid situations involving numbers and therefore less likely to develop adequate numeracy skills (see figure 2).

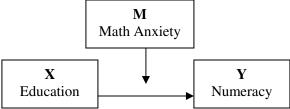


Figure 2. Moderator relationship

Testing for a moderation effect incorporates the use of regression modeling. In this study, numeracy skill (Y) is regressed on participants' reported level of formal education (X), math anxiety (M) as well as the interaction of formal education and math anxiety (XM) (Baron and Kenny, 1986; Wegner & Fabrigar, 2000). Moderator effects are indicated by the statistical significance of the interaction effect between participants' level of formal education and math anxiety. Statistical significance for the main effect of the moderator variable (M) is not essential for the determination of moderation effects (Baron & Kenny, 1986). The moderation effect of math anxiety on the relationship between formal education (explanatory variable) and numeracy skill (response variable) was assessed using multiple regression analyses as described above. Regression model main effects and the interaction of the two explanatory variables (formal education and math anxiety) were included in a multiple regression model (Baron and Kenny, 1986; Wegner & Fabrigar, 2000). Gender was also included in the model to control for the effect of gender. Regression modeling for a moderation effect of math anxiety on health context numeracy was not significant ( $\beta = -.025$ , p = 0.184) indicating that in this sample of older Canadian adults, math anxiety does not moderate the relationship between formal education and health context numeracy skill.

**Table 6. Moderation Analysis: Health Context Numeracy** 

	Std.				95% Confidence	
Parameter	В	Error	t	Sig.	Interval	
					Lower	Upper
					Bound	Bound
Intercept	2.9	1.3	2.1	.03	.23	5.5
Education	1.3	.48	2.8	.005	.42	2.3
Math Anxiety	.04	.05	.87	.38	05	.14
Education * Math anxiety	02	.01	-1.3	.18	063	.012

p = .05

### 2.7 Discussion

The main objective of this study was to determine health numeracy skills of a sample of community dwelling older Canadian adults. One key finding was that the gradient in participant numeracy skills was contingent on the numeracy assessment instrument used: numeracy skill assessed by the general context three-item scale was poorest, numeracy skill measured by the STOFHLA was greatest, and numeracy skill assessed by the eight-item health context scale fit between the two extremes. It is possible that the gradient observed with the simultaneous use of three numeracy scales reflected the range of skill (from basic to advanced numerical / statistical proficiency) proposed by Golbeck et al. (2005b). Our research also suggests that independent use of the identified numeracy measures may not fully reflect the numeric ability of older Canadian adults.

The study results further delineate the relationship between age and functional health literacy skill. Older Canadian adult participants had adequate health literacy skill as measured by the STOFHLA (prose and numeracy scores). The inverse association

found between aging and STOFHLA scores, most notably for participants 80 - 90 years of age agrees with previous findings of limited health literacy skills among U.S. adults 85 years and older (Schmitter-Edgecombe & Simpson, 2001; Sliwinski, 1997; Williams, Parker, Baker, Parikh, Pitkin, Coates, et al., 1995). We propose that the association between age and functional health literacy (STOFHLA) may be more a function of prose than numeracy skills. Whereas scores on STOFHLA prose decreased with older age, age did not differentiate ability on STOFHLA numeracy. Yet, numeracy skill as measured by both the three-item general context scale and the eightitem health context scale, were influenced by increases in age. Age associated decline in mathematical proficiency is a function of limited problem solving strategies, decline in temporal memory proficiency, slowing in cognitive processing, impairment of content recall, or complex counting tasks (Steen, 2001; Yagoubi, Lemaire, & Besson, 2005). That the STOFHLA numeracy subscale was not influenced by age in this study may reflect an emphasis on basic number recognition rather than utilization of strategies and skills associated with known age related decrements.

### 2.7.1 Numeracy Measured by the Three-Item General Context Scale

Math anxiety and education were the best predictors of numeracy skill measured by the three-item general context scale. In this study, men were better educated than women and, although there was no gender difference in terms of STOFHLA prose and STOFHLA numeracy scores, men scored better on the administered three-item general context and eight-item health context numeracy measures. The International Adult Literacy Survey (IALS) and the Adult Literacy and Life Skills Survey (ALLS) also reveal that men outperform women in terms of general numeracy skill (HRSDC, 2004; Statistics Canada, 2005c).

The study findings contribute to the literature regarding the influence of math anxiety on participants' numeric ability. Although self-reported numeric / statistical ability was not a predictor of older Canadians' numeracy ability, math anxiety influenced general context numeracy skill. The general context three-item numeracy questions, (i.e., "...the chance of winning a \$10 prize is 1%. What is your best guess about how many people would win a \$10 prize if 1000 people each buy a single ticket to...?") were structured similarly to math word problems studied in grade school educational curriculums (i.e., "If two cars leave the parking lot one hour apart..."), which tend to be unrelated to realistic life encounters and, for many, invoke anxiety (Steen, 2001). The math anxiety associated with assessed general context numeracy skill may reflect the perception that the three-item general context numeracy questions were more 'math-based' or abstract and, hence, more difficult. Poor preparation in mathematics invokes increased anxiety (Faust, Ashcraft, & Fleck, 1996) and this can discourage participation in math based course instruction (Cloer, 1981). This reciprocal relationship is self-perpetuating and limits numeracy development.

### 2.7.2 Numeracy Measured by the Eight-Item Health Context Scale

Education was a significant predictor of skill with both the general context three-item and health context eight-item numeracy scales. The relationship between fewer years of schooling and lower general context numeracy skill is well documented (HRSDC, 2004; Statistics Canada, 2000, 2005 c). Similarly, prose literacy, as measured by the STOFHLA, and education are positively correlated (Baker et al., 1999). Our finding that education is linked to numeracy skill as measured by the eight-item health context numeracy scale further contributes to the literature.

The eight-item health context numeracy scores also reflected variation in prose skill as measured by the STOFHLA. The link between reading comprehension and

general numeracy skill has been previously documented (Choi & Hannafin, 1997; Curcio, 1987; Silver, 1981) and our results suggest that a proficiency in prose health literacy as measured by the STOFHLA is also linked to numeracy skill contextualized to a health setting. Study findings also corroborate those of Lipkus et al. (2001) who report numeracy skill contextualized to health as better than general context numeracy skill (Lipkus et al., 2001). Despite this, both assessment instruments were seen to measure the same construct of "global numeracy" (Lipkus et al., 2001). Unlike general context numeracy skill, participants' health context numeracy skill was not influenced by math anxiety. It is possible that the better performance on the health context numeracy measure reflects the importance of context to participants' comprehension of Questions that position numeracy tasks within a numeracy-based information. commonplace or familiar context (e.g., health) rather than more abstract 'mathematics word problems' may reflect participant anxiety regarding self-efficacy in mathematics. That the numeracy tasks are embedded within a health context emphasizes the need for adequate prose skill. Moreover, context familiarity appears to enhance mathematical problem solving skill and improve outcomes on assessment scores (Schwartz, McDowell, & Yueh, 2004; Woloshin, Schwartz, Black & Welch, 1999).

# 2.8 Conclusion and Implications for Practice

To a large extent, statistics on health context numeracy skills are drawn from U.S. samples. Recognizing that both the Canadian healthcare and educational systems differ from those of the United States, this research provides an initial description of health based prose and numeracy skill among a group of independently functioning older Canadian adults. Assessing the influence of participants' math anxiety on numeracy skill is an additional novel contribution to the health literacy literature. That assessed math anxiety was associated with general context but not health context

numeracy highlights the need for continued research on numeracy assessment instruments and further consideration of the influence of math anxiety on participant comprehension of risk within healthcare information. Finally, given the link between prose health literacy and numeracy skill observed in this study, we suggest that a measure of prose health literacy should be considered when assessing health numeracy. The recently published NVS assessment tool (Weiss et al., 2005) shows promise in accommodating the need for a joint assessment of prose and numeracy skill. The current work reinforces the need for educational interventions focused on jointly improving health prose and numeracy skill.

Adequate health numeracy skill is a fundamental requirement for individual decision making about healthcare, disease prevention, screening, diagnosis, and treatment (Gurmankin et. al., 2004). Patients are required to comprehend increasingly complex health information. There is a gradient of numeracy skills for this group of older Canadians relative to the choice of numeracy assessment instrument used. It is possible that the use of one numeracy assessment tool independent of the others may not reflect the full spectrum of health numeracy. The research reported here highlights the need for continued assessment of health numeracy skill with other groups of adults who have diverse healthcare needs and who represent diverse populations. Important research opportunities include further development of the health numeracy model, additional validation of current numeracy instruments, and the development of comprehensive health numeracy assessments.

Finally, identifying patients' strengths and weaknesses with regard to health numeracy skill may lead to the development of focused health numeracy interventions and could potentially contribute to increasing self-efficacy in health literacy (prose / numeracy) skill. An example of this approach is the "Ask Me 3" programme which was developed to facilitate consumer comprehension through enhancing

communication within healthcare encounters (see <a href="www.Askme3.org">www.Askme3.org</a>). The Ask Me 3 programme encourages health care consumers to ask questions of clarification regarding their health status and also increases awareness among practitioners of consumer limitations relating to prose and numeracy skill. The National Institute on Aging (<a href="http://www.niapublications.org/tipsheets/risk.asp">http://www.niapublications.org/tipsheets/risk.asp</a>) offers strategies on how to interpret risk information found within public health information resources (i.e. newspapers, television, etc.).

# Chapter 3

# Risk Comprehension and Online Colorectal Cancer Information: Impact of Health Numeracy

#### 3.1 Abstract

Introduction: In this age of chronic disease and shared decision-making, individuals are encouraged to contribute to decisions about healthcare. Health literacy, particularly numeracy, is requisite to meaningful participation. Objective: Investigate the influence of health literacy skills, as well as math anxiety, attained education, and context of information on participant ability to comprehend Internet based cancer risk information. Method: Demographic details were collected on 140 older adults. Prose literacy was measured by the STOFHLA, math anxiety by AMAS, and numeracy by three different instruments. Risk comprehension was based on two web pages ('common' and 'uncommon') of cancer information. Multiple regression measured the influence of eight explanatory variables on risk comprehension scores. **Results:** Participants (91%) had 'adequate' health literacy (STOFHLA), high STOFHLA numeracy scores, moderate levels of health numeracy and math anxiety, but poorer general numeracy skill. The mean comprehension score for cancer risk information was 16.8/22. There was a significant difference between comprehension scores on 'common' (9.14/11) and 'uncommon' (7.64/11) web pages. Approximately 60% of the variation in comprehension scores was accounted for by the explanatory variables. Conclusion: Numeracy skill, ranging from basic to advanced proficiency, is required to understand online cancer risk information. With less familiar subject matter, prose literacy served to enhance numeracy skill. These findings have important implications for the design of online cancer information. Cancer information specialists are encouraged to exploit

the versatility of the Internet in constructing web-based information to accommodate the continuum of health literacy skill that currently exists.

# 3.2 Research Objectives

**Objective 1:** To determine how much of the variability in participant comprehension of colorectal cancer risk information is explained by participant skill in prose literacy, numeracy, math anxiety, and familiarity with the context of information.

# 3.3 Hypotheses

**Hypothesis I:** Familiarity with the context of information will increase participant risk comprehension accuracy.

This hypothesis is based on findings showing that individuals performed better on the numeracy assessment contextualized to healthcare despite finding the assessment instruments reflected the central construct of global numeracy, suggesting that numeric accuracy is not context specific.

**Hypothesis II:** Participant level of mathematics anxiety will be inversely related to comprehension accuracy of risk information. Higher anxiety will reflect decreased comprehension accuracy of risk information.

Numeracy success is dependent, in part, on practice and increased opportunity for use. In this case, mathematics anxiety will be used as a proxy measure of skill practice. Those with high math anxiety scores are assumed to avoid situations that involve number calculations, will be less inclined to seek out opportunities to utilize mathematical skills, and will have less practice and opportunity for skill utilization.

**Hypothesis III:** As participant numeracy test scores increase, risk comprehension accuracy will increase.

This hypothesis is based on research that finds lower numeracy scores linked to inaccurate risk perception. Individuals with low numeric skill are less able to accurately assess and personalize health risk. Schwartz et al. (1997) found that most women (27-88 years) with low numeric skill had difficulty correctly interpreting risk reduction data when asked to estimate their risk of death from beast cancer with and without screening mammography. The relationship between estimate accuracy and numeracy persisted even after adjusting for age, income, level of education and framing of the risk information. Women with low numeracy skill were unable to accurately assess their risk of breast cancer using two different scales for the measurement of risk perception (Schapira et al., 2004). Similarly, women who scored low in numeracy were more likely to overestimate their lifetime breast cancer risk (Davids et al., 2004).

The work presented in the remainder of this chapter is currently under review in a scholarly peer reviewed journal as:

Donelle, L., Arocha, J.F, Hoffman-Goetz, L. Colorectal Cancer Risk Comprehension of Older Canadians: Impact of Health Numeracy.

# 3.4 Introduction

Colorectal cancer is the fourth leading cause of cancer among Canadians and the second leading cause of cancer deaths (Canadian Cancer Society, 2006). Further increases in incident colorectal cancers are anticipated resultant to an aging population (Canadian Cancer Society, 2006). Yet, a national colorectal cancer-screening program has not been implemented in Canada. Consequently, health education and patient vigilance regarding risk awareness and preventive screening is advocated. Furthermore,

Canadians are increasingly using the Internet as an access point to healthcare information (Statistics Canada, 2004, 2005b). Consequently, the ability to understand cancer information serves as an essential healthcare skill and it is through the comprehension of healthcare information that individuals are able to engage in meaningful conversation with providers (Eysenbach, 1999).

The comprehension of risk contributes to improved healthcare by increasing knowledge, facilitating decision-making, motivating new behaviours, and changing existing behaviours (Eysenbach, 1999; Weinstein, 1999; Hay et al., 2005). With healthcare providers, consumers must assess their risk of disease and agree on 'best practices' appropriate to the determined risk (Charles et al., 1997). The need for shared-decision making is most compelling in cancer care where numerous treatment options exist, and where different benefits and risks must be evaluated under conditions of uncertainty (Charles et al., 1999). As a component of decision-making, risk comprehension involves the ability to judge the severity of potential harm which is dependent, in part, on the comprehension of numeric estimates of risk (Weinstein, 1999).

Health numeracy is "the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions" (Golbeck et al., 2005b, p. 375). Published accounts of numeric competency within healthcare indicate inadequate numeracy skill among young (Lipkus et al., 2001; Davids et al., 2004; Sheridan et al., 2002) and older adults (Woloshin et al., 2001; Sheridan et al., 2003). The consequences of decreased numeracy skill for breast, colon, head and neck cancer patients point to a diminished ability to accurately assess and personalize health risks (Schwartz et al., 1997; Davids et al., 2004; Weinstein et al., 2004).

Risk comprehension skill may be improved by familiarity of circumstance (Riche, Reid, Robinson & Hardash, 1991; Health Canada, 2003; Speros, 2005). Prior experience and familiarity of information enhances reader comprehension. For this reason, risk comprehension proficiency may also reflect a familiarity with terms and concepts associated with risk (e.g., relative risk) that constitute specialized content vocabulary (Kreuter, 1999; Jones, 2001). Yet, despite the link between prose and numeracy skill (Gal, 1993), none of the studies investigating numeracy skill and risk comprehension assessed prose health literacy skill.

Attained education, linked to numeracy skill, may influence risk comprehension skill. Although the statistical relationship between formal education and literacy skill is strong, many adults do not fit this pattern (HRSDC, 2004). Level of education as a proxy measure for literacy skill has been challenged as an accurate indicator (Baker et al., 1997; Statistics Canada, 2005c). Alternatively, evidence suggests that math anxiety invokes widespread apprehension with respect to working with numbers (Hopko, 2003). Knowing that numeracy skill is a practice-driven competence (Dingwall, 2000), math anxiety may also function as a predictor of risk comprehension ability.

Defined as a continuum of skill, health numeracy has been operationalized into four functional categories Golbeck et al., 2005b). Yet, within the cancer care literature, health numeracy skill has been assessed using a single general context assessment. In comparing skill using a general numeracy instrument to skill assessed using a health based numeracy tool, adults had greater success responding to health based numeracy questions (Lipkus et al., 2001).

Thus, the literature shows that there are outstanding measurement issues, application issues, and theoretical issues with regard to prose health literacy, health numeracy, and comprehension of risk. The rationale for this study follows from these

research gaps in the literature. The objective of this study was to determine the contribution of participants' prose literacy skill, numeracy skill, math anxiety, level of attained education, and familiarity of subject matter in determining their ability to comprehend Internet-based cancer risk information.

#### 3.5 Methods

# 3.5.1 Participants and Procedures

The research was introduced to participants as a project aimed at understanding participant comprehension of colorectal cancer information. A convenience sample of 140 older adults was recruited from Southern Ontario communities. For study inclusion, participants were required to: (1) read and comprehend in English, (2) reside independently within the community, and (3) be 50 to 90 years of age. Participants were excluded if they had been diagnosed with any type of cancer. Request for participation was publicized at regional public libraries, community seniors' centers, and through newspaper advertisements. Eligible participants were asked to commit to one face-to-face interview session with an estimated participant burden of 60 - 90 minutes. Participants were offered a \$40.00 stipend as reimbursement for miscellaneous costs. Details of the demographic characteristics of the 140 participants in this study are given in Donelle et al. (in press).

The first part of the interview was dedicated to collecting demographic details from the participants and scores on functional health literacy (Baker et al., 1999), general context numeracy (Schwartz et al., 1997), health context numeracy (Lipkus et al., 2001), and math anxiety (Hopko et al., 2003a). Functional health literacy was assessed using the shortened Test of Functional Health Literacy for Adults (STOFHLA) (Baker et al., 1999). This assessment consists of 36 prose multiple choice type questions and four numeracy questions. Each correct response scored 1 point.

The total prose score was multiplied by 2 (x36) for a range of scores from 0 to 72. The total numeracy score was multiplied by 7 (x 4) for a total score ranging from 0 to 28 resulting in a total score ranging from 0-100. A score from 0-55 indicates inadequate functional health literacy reflective of individuals who often misread very simple materials. Scores between 56-66 indicate marginal health literacy and scores between 67-100 indicate adequate skill (Baker et al., 1999). The STOFHLA has good internal consistency, reliability (Cronbach's  $\alpha = 0.98$ ) and validity compared with TOFHLA ( $r_s = 0.91$ ) and the Rapid Estimate of Adult Literacy in Medicine (REALM) ( $r_s = 0.80$ ) (Baker et al., 1999).

General context numeracy was assessed using a three-question general context numeracy assessment. This instrument assesses the concept of probability, the ability of participants to convert percentage to proportion, and to convert proportion to percentage (Schwartz et al., 1997; Lipkus et al., 2001; Sheridan et al., 2003). Participants' scores range from 0-3. This instrument has adequate internal consistency (Lipkus et al., 2001). Scores from this numeracy index are consistent with assessed National Adult Literacy Survey (NALS) quantitative literacy scores (Schwartz et al., 2005).

Health context numeracy was assessed using an eight-item assessment (Lipkus et al., 2001). The scale measures participants' ability to discern differences in magnitude of health risks, and perform mathematical operations using percentages and proportions contextualized to health (Lipkus et al., 2001). Participants score one point for each correct response with scores ranging from 0 to 8. Internal consistency was reasonable (Chronbach's  $\alpha = 0.74, 0.70$ , and 0.75) (Lipkus et al., 2001).

Finally, math anxiety was assessed using the Abbreviated Math Anxiety Scale (AMAS), a 9-item scale with strong internal consistency (Cronbach's  $\alpha$  = .90) and test-retest reliability (r = .85) (Hopko, 2003). Test item scores range from 1 (low anxiety) to

5 (high anxiety) with a maximum test score of 45. The test requires participants to indicate their anxiety level in mathematics-based situations (Hopko, 2003).

The latter part of the interview was devoted to the assessment of risk Participants read two separate web-pages of consumer-oriented, comprehension. colorectal cancer prevention information from the Canadian Cancer Society (CCS) web site. The web pages were selected for similarities in terms of the cancer type, font size, and readability. Web-page selection was based on the following criteria:  $(1) \ge 6$ numerical references, (2) numerical references in number or text form, (3) a maximum grade 12 reading level (determined by SMOG readability assessment) (McLaughlin, 1969), and (4) a maximum length of 3 pages. Validated readability assessment tools (i.e., Flesch Reading Ease (FRE), Gunning Fog, Fry readability Graph) are similarly based on formulas that account for sentence length (average number of words) and word length (number of syllables) (Meade & Smith, 1991). Computer software programs (i.e. Microsoft© Word) can calculate the FRE and Flesch-Kincaid readability scores. The SMOG readability assessment is a commonly used tool for evaluating readability (Friedman, Hoffman-Goetz, Arocha, 2004; Friedman & Hoffman-Goetz, 2003) and is advocated as a reliable assessment instrument by the U.S. National Cancer Institute (http://www.cancer.gov/pinkbook/page9).

Eligible web-pages were screened for information judged to be 'common' and 'uncommon'. 'Common' information included material widely publicized and easily accessible. Information in the 'common' web-page replicated general CCS introductory information available for all cancer types. For online seekers, this page was one of the first links within a list of colorectal cancer topics, was one page in length, and with a grade 10 SMOG readability score.

The second web-page focused on less common aspects of colorectal cancer: genetics. This information, 1 ¼ pages in length, scored a grade 11-12 SMOG rating.

Despite an increased awareness of hereditary influences on disease, public understanding of genetics is often limited (Richards, 1996; Lanine, Jayaratne, Sheldon, Kardia, Anderson, Feldbaum, et al., 2004; Boyd, Watkings, Price, Fleming & DeBaun, 2005). Consequently, CCS 'colorectal cancer and genetics' web-page was chosen to represent information considered 'uncommon' to the general public. Community cancer prevention education partners contributed to web-page selection.

Web-page information was printed on 8 ½ by 11 inch paper with 14 font type (see Appendix C). Printed versions were used to control for the potential confound of computer skill diversity. Mindful of web site 'updating', the printed pages ensured consistency of information over the course of the investigation.

Multiple-choice prose and numeracy questions, based on web-page content, were used to evaluate participant comprehension of the risk information. Prose and numeracy comprehension questions were written at a grade 8-9 readability and pilot tested with 30 individuals. Example multiple choice comprehension questions included: (1) "What does incidence mean?" (Answer: The total number of new cancer cases diagnosed each year), (2) "Familial Polyposis accounts for 1% of all colorectal cancers. If the total number of all cases equaled 10,000 how many cases would result from this?" (Answer: 100) (see Appendix D). Participants were allowed unrestricted use of the printed web pages to respond to the comprehension questions. Simultaneous presentation of the two web pages allowed the participant to self-select which page to begin with.

# 3.5.2 Statistical Analysis

All analyses were conducted with SPSS, Version 14.0 (SPSS, 2005). Descriptive statistics and participant scores for functional health literacy (STOFHLA), numeracy, and math anxiety were summarized. Multiple regression analysis was performed using:

(1) total risk comprehension scores (2) risk comprehension scores from the 'common' web page, and (3) risk comprehension scores from the 'uncommon' web page as response variables. Chosen *a priori*, explanatory variables included functional health literacy (STOFHLA), general numeracy, health numeracy, level of attained education, and math anxiety. The explanatory variables of age, self-rated English language skill, reading frequency, self-rated numeric / statistical understanding, and income were included in subsequent regression modeling. Gender was kept in all regression equations regardless of statistical significance.

The non-parametric Wilcoxon Signed Ranks test was used to determine differences between familiar and non-familiar web page test scores. The Mann-Whitney U test determined score differences between genders. In all analyses, a *P* value of 0.05 was accepted as different from chance alone.

# 3.6 Results

#### 3.6.1.Demographic Characteristics of Participants

Participants ranged in age from 50-90 years with 65% of participants ranging from 50-69 years. There were more women (n= 103, 73.6 %) than men (n= 37 males, 26.4%) and the majority of participants were married (48.6%), retired (63.6%), well educated (52.9% college or university degree), and at a lower annual income level (<\$35,000; 56.5%). Most participants (n=102, 72.9%) owned a computer and had access to the Internet. Further details of the demographic characteristics of the 140 participants in this study are given in Donelle et al. (in press).

# 3.6.2.Literacy and Numeracy Profiles of Participants

Table 7 gives the range of STOFHLA prose and numeracy skills. The mean total score was 89.7/100 (95% CI = 87.47, 91.93;  $\alpha$  = .92) with a prose score of 63.5/72 (95% CI =

61.54, 65.45), and a numeracy score of 26.2/28 (95% CI = 25.58, 26.81). Most participants scored in the highest STOFHLA category ('adequate' functional health literacy, n= 127; 91%). There were no significant differences between men and women on total STOFHLA scores (Mann-Whitney = 1797.5, p= 0.52), on the STOFHLA prose score (Mann-Whitney = 1878.5, p=0.89), or the STOFHLA numeracy score (Mann-Whitney = 1819.5, p=0.57).

General context numeracy scores revealed that 55% of participants had none or one correct answer, 29% had two correct answers, and 16% answered all three correctly. For the general numeracy context scores, the obtained alpha ( $\alpha$ ) reliability coefficient for the sample was 0.81. The mean score for health-context numeracy skill was 5.9/8 (95% CI = 5.54, 6.20). The obtained alpha ( $\alpha$ ) reliability coefficient for health context numeracy with this sample was 0.73. Men scored better than women on general context numeracy (Mann-Whitney = 1444.0, p = 0.02) and health context numeracy skills (Mann-Whitney = 1315.5, p  $\leq$  0.01).

Individuals expressed moderate math anxiety with a mean score of 23.8 (95% CI = 22.37, 25.21;  $\alpha$  = .91) from a maximum 45-point (see Table 7). Men ( $\overline{x}$  = 20.02, 95% CI = 17.71, 22.35) had less math anxiety than women ( $\overline{x}$  = 25.09, 95% CI = 23.41, 26.77) (Mann-Whitney =1136.50, p=0.001).

Table 7 Prose Literacy, Numeracy Literacy, and Math Anxiety Assessment Scores

Variable	Total Mean Scores (95% Confidence Interval)	
Math Anxiety	23.8/45 (22.37, 25.21)	
Health Numeracy	5.9/8 (5.54, 6.20)	
S-TOFHLA total	89.7/100 (87.47, 91.93)	
S-TOFHLA prose	63.5/72 (61.54, 65.45)	
S-TOFHLA numeracy	26.20/28 (25.58, 26.81)	
Variable	Total %	
S-TOFHLA level	Inadequate = 2 Marginal = 7 Adequate = 91	
General Numeracy	0-1 correct = 55 2 correct = 29 3 correct = 16	

# 3.6.3 Participant Subjective Risk Appraisal

Participants were asked to respond to questions assessing their subjective appraisal of risk. Almost 59% of participants suggested that a '1 in 16' lifetime probability of developing colorectal cancer constituted a 'high-risk' situation (response range = low, medium, high). More than three quarters of participants (76%) indicated that they would seek screening for colorectal cancer knowing that their lifetime risk for developing colorectal cancer was 1 in 14 for men and 1 in 16 for women.

Required to correctly list examples of 'first degree' family members, 30% of participants were unable to correctly complete the task. Participants with adequate

functional health literacy were better able to correctly respond to this task than those in the lower functional health literacy categories ( $\chi^2 = 10.02$ , df= 2, p = 0.004).

# 3.6.4 Risk Comprehension

The mean response score for total risk comprehension (combined 'common' and 'uncommon' web pages) was 16.8/22 (95% CI= 16.19, 17.38). There was no significant gender difference in risk comprehension test scores. There was a significant difference between participant scores on the 'common' and 'uncommon' colorectal cancer web pages (Wilcoxon Signed Ranks = -7.248, p < 0.01). Individuals scored better on the 'common' web based information (mean = 9.14, 95% CI = 8.85, 9.44) than the 'uncommon' information (mean = 7.64, 95% CI = 7.25, 8.03).

## 3.5.4.1.Regression Modeling of Risk Comprehension

To assess the contributions of STOFHLA health literacy skills, health context numeracy skills, general context numeracy skills, attained education, and math anxiety (*a priori* explanatory variable set) on total risk comprehension scores, a multiple regression analysis was performed (see Table 8).

**Table 8. Explanatory Variables Regarding Comprehension of Web based Colorectal Cancer Information** 

Explanatory Variable	Common Web Information β (95% CI)	Uncommon Web Information β (95% CI)	Combined 'Common' and 'Uncommon' Information β (95% CI)	
Gender	0.118 (-0.44, 0.67)	0.30 (-0.36,0.96)	0.00 (-0.92, 0.92)	
Age	-0.26 (-0.53, -0.006)*	-0.32 (-0.65, 0.009)	-0.678 (-1.14, -0.21)*	
Health Numeracy	0.401 (0.26, 0.54)**	0.38 (0.20, 0.56)**	0.838 (0.60, 1.07)**	
General Numeracy	-0.13 (-0.39, 0.14)	0.58 (0.28, 0.89)**	0.466 (-0.002, 0.89)	
S-TOFHLA Prose	0.014 (-0.01, 0.04)	0.07, (0.04, 0.09)**	0.067 (0.03, 0.11)**	
S-TOFHLA Numeracy	0.087 (0.02, 0.16)**	0.043 (-0.04, 0.13)	0.10 (-0.017, 0.218)	
Education	0.15 (-0.12, 0.43)	0.21 (-0.11, 0.53)	0.363 (-0.09, 0.82)	
Math Anxiety	-0.004 (-0.35, 0.028)	-0.006 (-0.4, 0.031)	-0.01 (-0.06, 0.04)	
Overall Model	F	df	$R^2$	
± Total	27.21	7	0.598 **	
+ <sup>1</sup> Final Total	35.24	5	0.568 **	
± "Common"	11.08	7	0.377 **	
<sup>+²</sup> Final "Common"	18.49	4	0.354 **	
± "Uncommon"	23.45	7	0.562 **	
<sup>+³</sup> Final "Uncommon"	34.675	4	0.507 **	

 $<sup>\</sup>beta$  = Beta Co-efficient, CI = Confidence Interval \* Significant at p < 0.05 \*\* Significant at p < 0.01

- ± Model Variables: math anxiety, general numeracy, health numeracy, STOFHLA numeracy, and STOFHLA prose, attained education
- † ¹Parsimonious Final Model = Age, Health Numeracy, STOFHLA Prose and Numeracy
- $+^2$  Parsimonious Final Model = Age, Health Numeracy, STOFHLA Numeracy
- † Parsimonious Final Model = Health Numeracy, General Numeracy, STOFHLA Prose

(Gender controlled in all models)

Additional regression modeling used the 'common' and 'uncommon' risk comprehension scores separately as response variables. Controlling for gender, approximately 60% of the variation in participant risk comprehension (total scores) was explained by STOFHLA prose skill, STOFHLA numeracy skill, math anxiety, attained education, general context numeracy skill, and health context numeracy skill (F=27.21, df= 7, p < 0.01,  $R^2 = 0.598$ ). Income, self-rated English language skill, reading frequency, and self-rated statistical understanding, did not contribute to the final model. The final regression model including participant age, STOFHLA numeracy skill, STOFHLA prose skill and health context numeracy skill accounted for 57% of the variance in participant risk comprehension scores (F = 35.244, df = 5, p < 0.01,  $R^2 = 0.568$ ).

Controlling for gender, 38% of the variation in risk comprehension of the 'common' web based information was accounted for by the *a priori* explanatory variable set (F= 11.08, df = 7, p < 0.01,  $R^2$  = 0.377). Further modeling revealed that health context numeracy, STOFHLA numeracy, and participant age produced the most parsimonious regression model (F=18.486, df = 4, p< 0.01,  $R^2$  = 0.354). No other explanatory variables significantly contributed to the regression model.

The *a priori* explanatory variable set accounted for 56% of the variation in risk comprehension of 'uncommon' web based colorectal cancer information (F=23.453, df =7, p < 0.01,  $R^2 = 0.562$ ). The most parsimonious model included: health context numeracy skill, general context numeracy skill, and STOFHLA prose skill, controlling

for gender (F=34.675, df = 4, p < 0.01,  $R^2$ = 0.507). No other explanatory variables significantly contributed to the regression model.

Almost 60% of the variability in total and 'uncommon' comprehension scores of cancer risk information was explained by numeracy and prose skill. Yet, only 35% of explained variation in risk comprehension of 'common' colorectal cancer information can be attributed to numeracy skill (prose health literacy was not a significant predictor).

#### 3.7. Discussion

While recognizing the influence of patient characteristics (i.e., social support, health status, affect) (Weinstein, 1999; Peters et al., 2006a) and presentation format (i.e., gain/loss framing, graphical vs. text) (Reid, Kardash & Robinson, 1994; Kreuter, 1999; Schapira, Nattinger, McHorney, 2001) on risk comprehension ability, this investigation focused on the influence of information context, math anxiety, level of attained education, and prose and numeracy skills on the ability of older Canadians' to understand Internet based colorectal cancer prevention information. Participants revealed adequate risk comprehension skill, with comprehension of 'common' cancer prevention information less challenging than information about cancer and genetics.

Participant numeracy performance appeared to reflect the hierarchy of proficiency reported by Golbeck et al., (2005b), and as described elsewhere (Donelle et al., in press). While no other published work has assessed risk comprehension of online cancer prevention information using the health context numeracy instrument, poor general context numeracy skill has been linked to decreased accuracy in assessing and personalizing cancer risk (Schwartz et al., 1997; Davids et al., 2004; Schwartz et al., 2004; Weinstein et al., 2004).

A model of health numeracy, characterized by four progressive levels of proficiency (basic, computational, analytical, and statistical) (Golbeck et al., 2005b) may offer an explanation for the observed differences in participant comprehension for the 'common' and 'uncommon' web pages. Although health context numeracy skill predicted comprehension success of both online colorectal cancer pages, basic (STOFHLA) numeracy ability was also predictive of participants' comprehension of 'common' online prevention information. In contrast, general context numeracy skill predicted comprehension of the more challenging or 'uncommon' information. Comprehension of 'common' web page information required participants to 'spot', for example, the value that signifies "the risk of death from colorectal cancer for men" (i.e., 1 in 14). The STOFHLA numeracy instrument is best aligned with the most basic numeracy skill category of number identification (Donelle et al, in press). participants responding to 'common' web page comprehension questions also required greater numeric proficiency to calculate the percentage of men dying from colorectal cancer, a skill level characteristic of the advanced categories in the health numeracy framework (Golbeck et al., 2005b; Ahlers-Schmidt, 2006).

Although the 'uncommon' web page of information also challenged participants' basic and advanced numeracy skill, STOFHLA numeracy skill was not a significant predictor. Given the lack of general public knowledge regarding genetic influences on colorectal cancer (Richards, 1996; Lanine et al., 2004), it is possible that the basic numeracy skill was perceived as more difficult due to a lack of knowledge content regarding the genetic basis of disease (Riche et al., 1991). Established evidence suggests that breadth of vocabulary and domain knowledge increase comprehension of information (Hirsch, 2003).

Topic familiarity and risk comprehension have previously been linked (Reid et al., 1994; Spires &Donley, 1998; Health Canada, 2003; Beirer et al., 2005). It is not

surprising then that prose health literacy skill contributed only to comprehension of 'uncommon' colorectal cancer information. Adequate vocabulary skills contribute to enhanced reader comprehension skills (Reid et al., 1994; Hirsch, 2003). The terms and phrases used within the genetic information may have required a vocabulary distinct from that needed to understand the 'common' web page.

In addition, personal connections to information enhances thinking about the content and promotes understanding through increased attention to the information (Spires et al., 1998). Participants in this study had no personal threat of colorectal cancer and, therefore, may have been less inclined to attend to educational colorectal cancer messages. Consequently, it may be important that health promotion messages incorporate repetition of less familiar terms and include examples and analogies of the concepts (Reid et al, 1994). The interactive capabilities attributable to online health sources (i.e., pop up text boxes, multi-media segments, ability to request more information) present an excellent avenue for unobtrusively incorporating information 'props'.

While math anxiety did not contribute to participant risk comprehension ability, increased age did predict poorer comprehension scores for the combined 'common / uncommon' risk assessment and for the 'common' assessment but not of 'uncommon' risk comprehension assessment scores. A recent evaluation of older adults' comprehension of web-based colorectal cancer information also revealed limited understanding of the intended message (Friedman et al., in press). The relationship between increased age and lower prose and numeric literacy skill has been previously established (Williams et al., 1995; Baker et al., 1999; Sheridan et al., 2003). Current findings are consistent with international analyses of adult prose and numeracy skill. In fact, an inverse relationship between age and literacy skills exists even after controlling for educational attainment (Statistics Canada, 2005c). Age, therefore, represents an

accumulation of life experiences influencing the development or loss of literacy skills whereby some older adults expand and others lose literacy skills, independent of educational attainment (Statistics Canada, 2005c).

The Adult Literacy and Life Skills Survey (ALL) reports educational attainment as an unreliable predictor of literacy skill (Statistics Canada, 2005c). Level of attained education as an explanatory variable was not a significant predictor of risk comprehension skill in the current study. Evidence suggests that a reciprocal relationship exists where those with low literacy proficiency are least likely to enlist in lifelong learning opportunities. For example, almost half of adult Canadians take advantage of continuing education learning opportunities whereas only about 20 percent of those operating at the lowest literacy levels participate (Statistics Canada, 2005a).

Approximately 76% of participants indicated that they would seek screening for colorectal cancer based on an awareness of their lifetime risk. However, recent statistics suggest that screening for colorectal cancer among Canadian adults 50 years and older is less than 15% (Canadian Cancer Society, 2006). While recognizing the inconsistency between actual screening for colorectal cancer and the intention to be screened, the number of older adults indicating their intention to have preventive screening after a single episode of reading information on colorectal cancer risk was promising. Alternatively, it was concerning that 30% of participants were unable to identify examples of 'first degree' family members from those listed in the 'cancer and genetics' information, and that this was directly linked to inadequate functional health literacy skill. Indeed, this finding takes on greater importance given current screening recommendations for all first-degree family members of individuals with known genetic markers for colorectal cancer (Canadian Cancer Society, 2006).

# 3.8. Conclusion and Implications for Practice

This research is the first to investigate the influence of health literacy skill, particularly numeracy skill, on the ability of older Canadians to comprehend online colorectal cancer prevention information. The findings revealed that a hierarchy of numeracy proficiency contributed to reader comprehension of Internet based prevention information on colorectal cancer risk. Health context numeracy skill was a consistent predictor of participant ability to comprehend risk within common as well as more challenging cancer prevention information.

Finding that participant risk comprehension was jointly facilitated by prose and numeric skill highlights the need for clarification of terms and concepts. By nature, prevention messages, invoking less personal meaning, may be enhanced by repetition of terms and detailed explanation of less familiar concepts to aid reader comprehension of the colorectal cancer prevention information. Recognizing that even basic numeracy tasks may be perceived as more demanding if positioned within an unfamiliar context challenges information specialists and web designers to construct web-based information to accommodate diverse health literacy skills (i.e., layer information using word links, video clips).

Within contemporary healthcare, individuals are encouraged to contribute to decisions about their health and their care. Thus, continued investigation is needed to refine the concept of health numeracy, develop comprehensive numeracy assessment instruments, and to further investigate the relationship between health prose and numeracy skills with all age cohorts, within various chronic illnesses, and among diverse ethnic groups.

#### **CHAPTER 4**

# General Discussion and Implications for Practice and Further Research

#### 4.1 Overall Findings

To my knowledge, this investigation is the first to explore the influence of health literacy, particularly health numeracy skill, on community dwelling older Canadians' ability to comprehend online colorectal cancer risk information. Health numeracy has been defined as "the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions" (Golbeck et al., 2005b, p. 375). Health numeracy has been modeled as four categories of progressive numeracy skill labeled Basic, Computational, Analytical, and Statistical (Golbeck et al., 2005b). Not mutually exclusive, these categories of skill are characterized as overlapping clusters of concepts differentiated by skill level, required number manipulations, and the extent of literacy involved (Golbeck et al., 2005b). Existing numeracy assessment instruments currently used by healthcare researchers (STOFHLA, general context numeracy, and health context numeracy instruments) appear to measure different aspects of health numeracy proficiency. In addition, current results underscore the influence of numeracy skill in participant comprehension of colorectal cancer risk information. This work also highlights the important interplay between prose health literacy and health numeracy in influencing older adults' understanding of online colorectal cancer risk.

Health literacy skill is currently recognized as a key determinant of health with low health literacy being a contributor to poor health (Nutbeam, 2000). Although health literacy consists of two main skill subsets (prose and numeracy), the conventional use of the term 'health literacy' has been in reference to prose literacy skill. The evolution of the health literacy concept is found in its multiple definitions (Ad Hoc Committee on

Health Literacy for the Council on Scientific Affairs, 1999; Nutbeam, 2000; Centre for Literacy Quebec, 2001; Speros, 2005). A standardized definition of the term 'health literacy' has yet to be realized. Distinguishing between health literacy subsets (prose and numeracy) acknowledges the unique contribution of each skill to health literacy expertise. A concentrated focus on prose health literacy has been well documented within the research literature whereas health numeracy, as an area of health investigation, is only now gaining momentum (Golbeck et al., 2005b).

# 4.2 Prose Health Literacy / Numeracy Skill

The 140 older community dwelling Canadians who participated in this study had well developed functional health literacy skill (health prose and numeracy) as measured by the STOFHLA. The majority of study participants (91%) ranked in the highest STOFHLA skill level indicative of their ability to comprehend written and verbal healthcare directions, to follow established healthcare plans and to accurately administer medications (Nurss et al., 1995; Williams et al., 1995). These findings contrast with current U.S. health literacy estimates (Paasche-Orlow et al., 2005; Baker et al., 2004; Baker et al., 1999; Williams et al., 1995). Estimates of functional health literacy skill in U.S. participants revealed that one third to one half of adult participants had poor functional health literacy skill scoring as inadequate or marginally health literate (Baker et al., 1998; Williams et al., 1995). The existing differences in functional health literacy skill between the two populations may simply reflect demographic factors. The current study assessed older Canadian adults who were well educated, of largely Anglo-Canadian heritage, and at the lower income level. A systematic review of eighty-five U.S. based studies on health literacy found that 26% of assessed Americans had low health literacy with an additional 20% rated as marginally health literate (Paasche-Orlow et al., 2005). The U.S. estimates of limited health

literacy skill included overrepresentation of older aged individuals, people of African American heritage, and those with little formal education and low income in the studies examined (Paasche-Orlow et al., 2005). These demographic differences may offer some insight into the observed Canadian – U.S. differences in assessed health literacy skill.

Low health literacy infers difficulty in reading, understanding and interpreting even the simplest health information. Without assistance from healthcare practitioners, individuals low in health literacy were considered at risk for: (1) making an error in taking medications, (2) having difficulty in following diet and exercise instructions, (3) having little understanding of established care plans, and (4) increased hospitalizations and use of emergency department services (Baker et al., 2004; Baker et al., 1998; Nurss al., 1995). There is also evidence that low functional health literacy (STOFHLA/TOFHLA) is linked to: (1) disease misperceptions where low literate HIV positive individuals committed to their HIV treatment protocols believed their risk of sexually transmitting the virus was a decreased and subsequently believed that safer sex practices could be relaxed (Kalichman et al., 2000; Kalichman, Ramachandran, & Catz, 1999) (2) poorer patient provider communication in the area of information clarity regarding diabetes, explanation of the health condition and explanation of processes of care (Schillinger et al., 2006), (3) a decreased willingness to read and also to seek out written medicine information (Koo et al., 2006), (4) poor glycemic control and higher rates of retinopathy among diabetes patients (Schillinger et al., 2004; Schillinger, Grumbach, Piette, Wang, Osmond, Daher, Palacios, Sullivan, & Bindman, 2002) (5) decreased willingness of asthma patients to participate in personal health decisions about their own healthcare (Mancuso & Rincon, 2006) and (6) limited knowledge regarding personal health conditions and treatment options for individuals with asthma, diabetes, congestive heart failure, and hypertension (Gazmararian et al., 2003).

Moreover, low functional health literacy was also associated with poor quality communication regarding cancer (Davis et al., 2002). Health literacy skill is related to individuals' ability to gain value from cancer control messages, materials, and conversations. With low literate individuals there is a greater likelihood that they will less knowledgeable about cancer control issues, and express greater misunderstanding regarding their susceptibility to cancer and the advantage of early detection. Taken together, these factors may also influence participation in preventive cancer screening behaviours (Davis et al., 2002). Consequently, low literate individuals are more likely to present with advanced stages of cancer at the time of diagnosis. Individuals with low health literacy experienced greater mortality from cancer disease than higher literate individuals and this has been associated with diminished screening, a lack of acceptance and / or compliance to recommended treatment protocols (Davis et al., 2002). Poor health literacy skill is specifically linked to limited health vocabulary, decreased knowledge of anatomy, and minimal understanding of cancer control concepts such as screening and early detection; knowledge of cancer disease is often inaccurate, and individuals are confused about cancer screening options (Davis et al., 2002). In Canada, less than 15% of adults 50 years of age or older are receiving screening for colorectal cancer (CCS, 2006). Current CCS (2006) recommendations include screening for all first-degree family members of individuals with known genetic markers for colorectal cancer. Yet, it was troubling to note that 30% of study participants were unable to identify examples of 'first degree' family members from those listed in the 'colorectal cancer and genetics' information.

Within the shared model of healthcare, information sharing is a prerequisite to the process of shared decision-making (Charles et al., 1997). The physicians' role includes sharing information on options, risks, and benefits of possible treatment and ensuring consumer comprehension of the information. Thus, the physician role as a

credible information source forms a core element of the shared decision-making process. Interestingly, the majority (76%) of highly health literate participants in the current study indicated an intention to obtain colorectal cancer screening after reviewing online CCS colorectal cancer lifetime risk estimates. Health information from the Internet has been used to supplement or compliment information given from healthcare professionals (Cline & Haynes, 2001). Online health information serves as a credible source of healthcare knowledge permitting information seekers access to trustworthy scientific (e.g., Medline) and institutional (e.g., Sunnybrook Health Sciences Centre) sources (Eysenbach, 2003; Cline & Haynes, 2001; Fox & Rainie, 2000). Surveyed responses from approximately 6500 Internet users revealed that online health information contributes to self-care decisions (Fox & Rainie, 2000). Furthermore, online health seekers indicated that health information from the Internet influenced their decisions about whether to visit a physician, how to treat an illness or condition, and led them to ask new questions or to seek a second medical opinion (Fox & Rainie, 2000). For many cancer patients use of the Internet persists beyond the high information needs that occur at the time of diagnosis remaining an important source of cancer information throughout the course of disease (Eysenbach, 2003). In addition to accessing healthcare information, the Internet serves as a way to communicate with physicians, and connect with virtual support networks. This contributes to patients' increased sense of control, reduced anxiety, improved compliance, participation in selfcare and increased feelings of safety and security (Eysenbach, 2003). Although the current study did not assess frequency of online use, most study participants (73%) indicated that they owned a computer and all computer owners had established Internet access.

### 4.2.1 Health Numeracy

Numeracy can be differentiated from mathematics in a significant but subtle manner (Dingwall, 2000; Steen, 1999, 2001b). Characterized as the application of basic mathematical concepts for purposes of everyday problem solving, numeracy is reflected in the practical application of basic mathematical concepts rather than an understanding of abstract mathematical theory (Dingwall, 2000; Steen, 1999, 2001b). There was wide variation of numeric competency. Older adults had high functional health literacy (prose and numeracy) skill but performed less well on more complex numeracy tasks (i.e., identifying an appointment date vs. calculating a 0.005 risk of disease among 10,000 people). Only 16% of participants answered all three general context numeracy questions correctly. Just over half (55%) of participants answered either none or one question correctly suggesting limited general context numeracy proficiency. Health context numeracy skill improved over general context numeracy skill with 24 % of individuals correctly responding to all health context numeracy questions. Close to 80% of older adults in this study achieved a perfect score on the STOFHLA numeracy subcomponent. Participant skill is reflected in increasingly poorer scores as the numeracy measures move from greatest to least application to the healthcare context. Participants scored best on the STOFHLA, poorest on the general context numeracy scale and moderately well on the health context numeracy scale reflecting a hierarchy of numeracy proficiency related to the measurement tool.

The findings support the model of numeracy proposed by the IALS / ALLS that frames numeracy as a continuum of expertise ranging from limited to superior proficiency (HRSDC, 2004; Statistics Canada, 2005a). These findings also provide early empirical support for the recently proposed model of health numeracy (Golbeck et al., 2005b). Health numeracy defined as a continuum of skill incorporates categories of increasing proficiency defined as 'Basic' numeracy. Skill at this fundamental level

reflects the ability to identify numbers but does not include number manipulation (i.e., identifying the date of an appointment). 'Computational' health numeracy skill incorporates the ability to perform basic number calculations or arithmetic. 'Analytical' health numeracy involves the ability to interpret health context data, and 'Statistical' health numeracy reflects an understanding of basic biostatistics (i.e., understanding probability concepts, life expectancy statistics, etc.). This investigation of health numeracy skill revealed that currently used numeracy assessments instruments tap into the range of numeracy skill categories.

Participant numeracy skilled measured by STOFHLA seemed to align best with the 'Basic' category of the health numeracy model. The 'Basic' health numeracy category involves the ability to identify numbers and make sense of quantitative data but does not require number manipulation (Golbeck et al., 2005b). Older adults demonstrated excellent basic health numeracy skill as evidenced by their ability to identify correct dates and times for medical appointments. 'Computational' health numeracy was also evident in participant ability to calculate the correct timing for medication administration. Age associated decline in mathematical skill as a function of limited problem solving strategies, temporal memory deficiency, slower cognitive processing, impaired content recall, and complex counting tasks (Steen, 2001b; Yagoubi et al., 2005) did not appear to compromise basic number identification and basic calculation tasks demanded of the STOFHLA.

Numeracy skill assessed by the health context numeracy and general context numeracy instruments (see appendix J and K) appeared to be more challenging, perhaps drawing on expertise attributable to the categories of health numeracy further along the numeracy continuum: computational, analytical or statistical categories (Golbeck et al., 2005b). Knowledge demands of these more advanced numeracy categories include: (1) the ability to conduct simple manipulations of numbers, items or visual elements

(Computational), (2) the use of inference and estimation along with an ability to understand proportions, and frequencies using multiple sources of information (Analytical), and (3) the ability to compare information presented in different formats, to critically analyze health information such as risk and life expectancy (Statistical). Thus, age related decline in general context and health context numeracy skill may be related to possible cognitive decline coupled with the increased cognitive demands of the advanced numeracy tasks. There is also evidence that multiple numeric concepts within a single task demands a more advanced level of numeric comprehension than required to understand a single numeric concept (Ahlers-Schmidt et al., 2006). For example, individuals with low numeracy skill may understand concepts such as range, percent, and risk but their ability to comprehend diminishes when these same concepts are combined to create increasingly complex statements such as "this represents a reduction in the absolute risk of recurrence of 2% to 3% or from 7% to 10%" (Ahlers-Schmidt et. al., 2006, p. 97). Given the health numeracy model and the comprehension challenges of simple vs. combined numeracy concepts, a review of current health numeracy assessment instruments is warranted.

Older participants scored better on the health context numeracy assessment than on the general context assessment. This replicates the work of Lipkus et al. (2001), who also found that adult participants scored better on the health context numeracy than on the general context numeracy assessment. General context numeracy questions may simply reflect the most complex category of health numeracy (i.e., Statistical) (Ahlers-Schmidt et al., 2006). However, it may also reflect a greater math anxiety not experienced with the health context numeracy assessment. General context numeracy skill, but not health context skill, was significantly associated with increased math anxiety. Arguably, the general context numeracy assessment questions were presented as math word problems, and resembled questions found in standard educational math

curricula; the format of these questions unrelated to realistic life encounters often invoke anxiety (Steen, 2001b). Moreover, evidence indicates that math anxious individuals tend to develop negative attitudes regarding their problem solving abilities and avoid situations that require use of math skills (Ashcraft & Faust, 1994; Ashcraft & Kirk, 2001). The hypothesis that math anxiety (as a function of skill utilization) moderates the relationship between level of education and health context numeracy skill was not supported in this study. Yet, increased participant math anxiety influenced general context numeracy skill. This may reflect participants' perception of the general numeracy questions as a test of 'classroom math' knowledge (i.e. knowledge related to the resolution of a mathematics problem). Math anxiety was not a predictor of participant skill in health context numeracy. However, similar mathematical manipulations (e.g., conversion of probability to percentage) were demanded of both the general and health context numeracy assessments. Success on the health context numeracy assessment was reflected by participants' adequate prose health literacy. The majority of participants in the current study had well developed prose health literacy skill. Perhaps the lack of participant math anxiety combined with satisfactory prose skill enabled greater participant success on the health context numeracy assessment.

Furthermore, participant level of attained education was positively associated with both general numeracy and health context numeracy skill such that greater numeracy skill corresponded with greater years of formal education. These findings indicate that level of education is an important component in the development of health numeracy skill. Math knowledge, taught within formal educational settings, may be foundational to the development of numeracy skills required of individuals to manage the increasingly complex healthcare tasks. This calls for greater collaboration between education and healthcare sectors to provide a curriculum of learning where mathematics is taught through application to issues of contemporary healthcare.

The STAT-Interest and the STAT-Confidence tests measure participant interest in and confidence in using healthcare data (Woloshin et al., 2005). Investigations using these scales show that respondents were highly interested and expressed high confidence in their ability to interpret medical statistics. Researchers cautioned that participant interest and confidence with medical statistics does not infer numeric ability but stated, "the extent to which confidence relates to ability is crucial. If confidence relates to ability, communicators could encourage those with too little confidence, and caution those with too much" (Woloshin et al., 2005, p. 996). Older adults in the current study were asked to describe their ability to understand numerical/statistical information as: excellent, very good, good, fair, or poor. The majority (93%) rated their numeric / statistical comprehension as good to excellent. Yet, self-rated numeracy comprehension did not predict participant numeracy skill. Self-reported assessment of reading and mathematical skills have been judged higher than actual assessed ability (Golbeck, Ahlers-Schmidt & Paschal, 2005a). A single assessment of self perceived statistical comprehension does not predict numeracy proficiency.

There was no significant correlation between age and basic health numeracy skill (STOFHLA). However as age increased STOFHLA prose health literacy skill decreased, particularly for community dwelling older adults 80+ years of age. Similar results of age related declines in prose health literacy within a group of high income, well educated, healthy older adults have been reported elsewhere (Benson & Forman, 2002). Of these older adults, approximately 70% of participants had adequate functional health literacy skill and similar to current findings, there were no health literacy skill differences between men and women.

### 4.2.2 Assessment of Health Numeracy

To date, the general context numeracy assessment tool has been used as the gold standard measure of health numeracy in part due to the efficiency of test administration (3 questions), the focused assessment of risk, and the lack of available alternatives. However, findings from this present study indicate that the use of a single numeracy assessment tool does not fully capture health numeracy skill. Further assessment of the current numeracy instruments is required to determine what aspect of numeracy skill is being measured. Using the proposed health numeracy model, the combined use of the STOFHLA numeracy subscale, the health context numeracy, and general context numeracy assessment instruments offer a more complete appraisal of health numeracy skill than an individual assessment instrument.

Another instrument, the 'Newest Vital Sign' (NVS), was recently developed to assess both prose and numeric health literacy (Weiss et al., 2005). Available in English and Spanish versions, the instrument consists of six assessment questions based on participant comprehension of an ice cream nutrition label. This instrument has been reported as reliable (Cronbach  $\alpha > 0.76$  in English and 0.69 in Spanish) and accurate for prose and numeric health literacy. This instrument may be a sensitive test for screening persons with limited literacy skill. A score of <2 on the NVS-English had a sensitivity of 72% and specificity of 87% for predicting limited literacy (TOFHLA score <75), whereas a score of <4 had a sensitivity of 100% and a specificity of 64%. Investigators state that the NVS instrument specificity may result in overestimating the percentage of patients with limited literacy, but indicated that use of the instrument will alert test administrators to patients who may need more attention (Weiss et al., 2005). Those scoring >4 on the NVS have adequate literacy as measured by the TOFHLA. A score <4 on the NVS, signifies the possibility of limited literacy. Cautionary interpretation of NVS scores < 2 is recommended. Respondents scoring < 2 have a greater than 50%

chance of having marginal or inadequate literacy skills (Weiss et al., 2005). A further advantage of NVS is the estimated 3-minute administration time with low respondent burden. However, there are no data on what aspect or construct of numeracy NVS measures. Continued research is needed to further identify the numeracy skill categories assessed by each numeracy instrument with the goal of developing a single, more comprehensive health numeracy assessment.

#### 4.2.3 Risk Comprehension and Numeracy

"Risk is a concept that denotes a potential negative impact to an asset or some characteristic of value that may arise from some present process or future event. In everyday usage, "risk" is often used synonymously with the probability of a loss or threat. In professional risk assessments, risk combines the probability of an event occurring with the impact that event would have and with its different circumstances"(<a href="http://en.wikipedia.org/wiki/Risk">http://en.wikipedia.org/wiki/Risk</a>). Risk comprehension involves the ability to understand hazards or risk, with the hope that this understanding will aid in improved decisions about the need for action or help to choose among alternative actions (Weinstein, 1999). Individuals need at a minimum "information about the nature and likelihood of potential ill effects, about the risk factors that modify their susceptibility, and about the ease or difficulty of avoiding harm" (Weinstein, 1999, p. 15).

The literacy demands of our 'information age' healthcare system require increasingly greater knowledge sophistication (Statistics Canada, 2000; Steen, 1999). Access to and comprehension of healthcare information are integral components of healthcare decision making (Charles et al., 1997; Rothman & Kiviniemi, 1999). The patient-provider relationship is characterized by the shared communication, personalized interactions, and transparency of treatment decision-making (Berry,

Seiders & Wilder, 2003; IOM, 2001). Recognition of 'information age' demands and the shared decision making model of healthcare have heightened awareness of the need for improved health literacy (Ad Hoc Committee on Health Literacy, 1999). While patient characteristics such as emotion, personal values, social support, current state of health, personality, and cognition, (Peters et al., 2006a; Weinstein, 1999) and presentation format such as gain/loss framing, verbal vs. written, and graphical vs. text (Kreuter, 1999; Reid et al., 1994; Schapira et al., 2001) are important attributes of adult risk comprehension ability, there are few studies investigating the relationship between cancer risk comprehension and health numeracy (Golbeck et al., 2005b). The current study begins to address this gap in the research literature.

Current findings indicate that older adults had relatively good risk comprehension skill, with better understanding of 'common' information over 'uncommon' web based information. Numeracy skill played an important role in the comprehension of online colorectal cancer risk information. The purposeful use of 'common' and 'uncommon' online colorectal cancer information was designed to evaluate the influence of context familiarity on reader comprehension of cancer risk information. 'Common' online colorectal cancer information represented widely publicized, easily accessible material, on the prevalence and incidence of colorectal cancer within the Canadian population from the Canadian Cancer Society (CCS) website (2005). The 'uncommon' web page focused on less widely publicized aspects of colorectal cancer, namely, genetics and colorectal cancer. The CCS genetic based colorectal cancer information was chosen to represent information deemed 'uncommon' to the general public. The web page of information linking genetics and colorectal cancer was appraised as 'uncommon' based on existing analysis of public understanding of genetics (Boyd et al., 2005; Lanine et al., 2004; Richards, 1996; Wideroff, Vadaparampil, Greene, Taplin, Olson & Freedman, 2005) and with

consultation of community partners in cancer prevention and early detection (CPEDN-Waterloo Region). Despite claims of increased awareness, public understanding of genetics is often limited.

The three measures of numeracy did not equally assess comprehension of colorectal cancer risk. Numeracy skill, assessed by the health context numeracy instrument, was a significant predictor of participant comprehension of both 'common' and 'uncommon' web pages of colorectal cancer information. General context numeracy skill was a significant predictor of risk comprehension regarding the genetic influences of colorectal cancer but did not reflect participant comprehension of the 'common' colorectal cancer information. Health context numeracy skill contributed to risk comprehension of information defined as 'common' and for the less common genetic information. Further research is required to determine whether the general context numeracy instrument assesses skills superior to the skill tapped by the health context numeracy instrument. Participants had poorer comprehension of the genetic colorectal cancer information than the general descriptive web page of colorectal cancer information. Increased understanding of health numeracy model categories and of appropriate assessment instruments is required.

Despite similar numeric task demands, older adults' comprehension of 'uncommon' or genetic colorectal cancer information was poorer than their comprehension of 'common' information. Greater prose health literacy skill among participants was associated with better understanding of the 'uncommon' risk information but not of the 'common' risk information. This may reflect interplay between numeracy and prose health literacy skill required for comprehension of unfamiliar or less common colorectal cancer information. It is possible that numeracy tasks seemed more complex to participants not because of increased numeric difficulty but because of inadequate prose literacy skill or lack of familiarity with the vocabulary

or health situation (i.e., lack of familiarity with genetic based cancer). Domain or topic specific knowledge increases a reader's understanding of information by allowing the reader to link novel with previously learned information; moreover, breadth of vocabulary and domain knowledge are significant components to increased comprehension of information (Beier & Ackerman, 2005; Hirsch, 2003; Reid et al., 1994; Samuelstuen & Braten, 2005; Spires et al., 1998). As Hirsch (2003, p.3) has stated, "...knowledge about the topic speeds up basic comprehension and leaves working memory free to make connections between the new material and previously learned information...". Participant comprehension is also negatively influenced by the use of technical words or unfamiliar medical terminology and readers with higher vocabulary skills have greater recall of information (Reid et al., 1994). It may be that the cognitive burden associated with comprehension of unfamiliar colorectal cancer information in those with weak prose literacy skill was greater than the burden for those with greater prose literacy skill. As a result, weak prose literacy skill may detract from the participants' cognitive capacity making comprehension of online cancer risk information more challenging.

Recognizing patients' need for specialized cancer vocabulary framed the development of the 'Single Item Literacy Screener' (SILS) (Morris, MacLean, Chew, & Littenberg, 2006) and the 'Stieglitz Informal Reading Assessment of Cancer Text' (SIRACT) (Agre, Stieglitz, & Milstein, 2006). The SILS instrument consists of a single item that asks "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?" Respondents chose to answer either 1-Never, 2–Rarely, 3–Sometimes, 4-Often, and 5-Always. This instrument identifies adults who require assistance with printed health material. The SIRACT evaluates adults' level of reading comprehension of cancer related information. The SIRACT consists of five components: (1) a word recognition

test, (2) a series of graded reading passages based on various cancer topics, (3) a set of five comprehension questions for each passage of text, (4) an assessment of readers' familiarity with the cancer information, and (5) an assessment of reader interest in the cancer information. While neither of these instruments included an assessment of health numeracy, content knowledge in the area of health and cancer is specifically recognized. Essential requirements for the achievement of adequate health literacy skill are domain specific vocabulary skills (e.g., cancer terminology) and an organizing framework (e.g., cognitive model) developed from previous interactions within healthcare settings in order to make sense of available healthcare information (Speros, 2005).

There was an age related decline in risk comprehension by the participants of the common genetics information but not for the uncommon colorectal cancer web page. This may be related to the complex numeracy demands for comprehension of the common colorectal cancer information (i.e., "The percentage of deaths from colorectal cancer in 2005 for all Canadians is 0.02% and the percentage of new cases in 2005 among all Canadians is 0.06%. Are there more people developing colorectal cancer than there are people dying from it?"). Multiple numeric concepts demand an advanced level of numeric comprehension (Ahlers-Schmidt et.al., 2006). Both health context numeracy and general context numeracy skill predicted older adult comprehension of uncommon cancer information. Interpreting these findings within the continuum model of health numeracy, health context and general context numeracy tools likely tap high level numeracy skills (i.e. analytical and statistical tasks) that may be more susceptible to age related decline. Age related decline in numeric skill is a function of limited problem solving strategies, decline in temporal memory proficiency, slower cognitive processing, impaired content recall, or complex counting tasks (Yagoubi et al., 2005).

Multiple numeracy demands and heightened prose literacy demands of less familiar information may challenge the cognitive capacity of older adults in the study.

This investigation assessed health literacy – prose and numeracy skill of older Canadian adults in relation to comprehension of online colorectal cancer information. A low level of functional health literacy (STOFHLA) has been associated with limited knowledge, and misperceptions of disease, and treatment options. Low literate individuals are less able to gain value from cancer prevention messages, materials, and conversations. In the current study older Canadians had well-developed functional health literacy (STOFHLA) skill. These findings contrast with functional health literacy prevalence estimates from the U.S. Demographic variations among assessed populations may reflect these skill differences.

Three numeracy assessment instruments were used to measure participant numeracy skill resulting in a hierarchy of skill contingent on the numeracy assessment instrument used. Numeracy skill assessed by the general context scale was poorest, numeracy skill measured by the STOFHLA was greatest, and numeracy skill assessed by the health context scale fit between the two extremes. This hierarchy of skills may mimic the continuum of skills described by Golbeck et al. (2005b) in the model of health numeracy. Greater math anxiety was associated with lower general context numeracy skill in this population. There was also interplay between prose and numeracy skill where greater prose health literacy contributed to better health context numeracy skill. Numeracy skill contributed to participant ability to comprehend online colorectal cancer information. Common or familiar colorectal cancer information was easier to understand than the less common information on colorectal cancer. Finally, prose health literacy skill was important in enabling participant comprehension of less common online colorectal cancer information.

## **4.3 Study Limitations**

There are limitations to this study. First, the study focused on colorectal cancer only. Colorectal cancer was chosen for its gender-neutral status and because of its high prevalence and high mortality rates among Canadians (Canadian Cancer Society, 2006). Evidence indicates that existing online information on colorectal cancer is written at high readability levels and that comprehension by older adults of online colorectal cancer information is poorer than prostate and breast cancer online information (Friedman, Hoffman-Goetz, & Arocha, 2006). On the other hand, the online information used in the study reflects 'real life' comprehension tasks of older online colorectal cancer information seekers and provides a snapshot of participants' understanding of currently available colorectal cancer information.

A second limitation of this study was the population recruited for participation. The voluntary nature of participation may have reduced representation of individuals with basic literacy who have less confidence in their literacy skills. Alternatively, literate individuals may be more likely to volunteer for a study on comprehension of health information. Using a convenience sample restricts the generalizability of the findings and the results cannot be considered as definitive of the larger older adult population. Nevertheless, there was diverse representation of socio-economic status of participants in this study providing a cross section representation of seniors.

A third limitation of this study is that the risk comprehension skill of this convenience sample of seniors living independently in the community may be different from those who are ill. Illness and disability can affect an individual's cognitive reasoning and decision-making skill altering the ability to accurately comprehend risk information (Cassell, Leon, & Daufman, 2001). Similarly, the literacy skills of participants are not representative of younger Canadians. Therefore, the current findings are representative of a 'well' rather than a health compromised group of

seniors. Similarly, the use of a convenience sample of individuals from local libraries and senior centres may have discouraged older adults who lacked transportation (e.g., those who cannot drive, were physically disabled). Individuals who did not frequent the libraries or senior (community) centres would also have limited representation within the study. Nevertheless, public transportation (i.e., on bus route) was available at each location and although required for only one interview, each location was wheelchair accessible. Hence, this convenience sample also reflects a group of relatively mobile, active, older adults.

A fourth limitation is that the assessment of older adult literacy skills does not reflect younger Canadians. Given the higher incidence rates of colorectal cancer for older Canadians, our study was therefore limited to adults 55 years and older. Therefore, the current findings are representative of a older rather than a younger group of Canadians.

A fifth limitation relates to gender differences. Although gender related differences in numeracy skill have been previously reported (IALS, ALL), there is a potential bias regarding higher math anxiety scores, lower general context and health context numeracy skill within the sampled population. This may be due to the higher percentage of women (74%) compared to men (26%) included in this convenience sample of participants.

An additional limitation is the lack of instrument validation of the risk comprehension test questions. This study concentrated on health literacy influences on risk comprehension. Accordingly, the comprehension questions were designed from the information in the colorectal cancer web pages to capture participant understanding of the intended cancer message using prose literacy (i.e., "what does incidence mean?") jointly with an understanding of health numeracy (i.e., what % of men died from colorectal cancer?"). The research team, including our community partners, reviewed

the comprehension test questions (providing contribution to face validity and content validity) and the questions were piloted (then refined) with 30 research participants using participant feedback for instrument revision.

A seventh important limitation of this work is that two of the instruments used (three-item general context and eight-item health context numeracy indexes) have not been well validated in the published literature. However, at the time of establishing this study protocol, the general context and health context numeracy indexes were the only available numeracy skill assessments (Estrada et al., 2004; Lipkus et al., 2001; Schapira, Davids, McAuliffe, & Nattinger, 2004; Schwartz et al., 1997; Schwartz et al., 2004; Woloshin et al., 2001; Woloshin et al., 1999). An additional assessment tool, the Newest Vital Sign, was introduced recently (Weiss et al., 2005), after the study protocol was initiated. In addition, the STOFHLA draws on and incorporates sample questions from a U.S. rather than a Canadian healthcare context. Yet, the STOFHLA is currently the only available standardized measure of functional health literacy.

An eighth limitation relates to Golbeck's et al., (2005b) model of health numeracy. None of the numeracy indices used in this study measured either the full construct of numeracy or that of health literacy. The eight-item health numeracy index replicates the numeracy tasks of the three-item scale, altering the context of information from a general to a health-based perspective. Lacking a broad spectrum numeracy assessment, three instruments were utilized in the current study in an effort to compensate for the lack of a single, comprehensive numeracy measurement tool appropriate for health based research. The assessment of health numeracy skill was limited by use of the three measurement instruments and may not be representative of the full construct of health numeracy. Alternatively, the use of multiple numeracy measures constituted the range of numeracy instruments currently used within published research.

A ninth limitation relates to development of the health numeracy concept. As an independent research focus, health numeracy is gaining research attention but is best described as "a work in progress" (Golbeck et al., 2005b). The model of health numeracy as hierarchical categories of numeric skill requires empirical support. As a result, the three numeracy measures represented those instruments that were available at the time of study initiation and were used to ensure comprehensive assessment of participants' numeracy skill. Without agreement on what this construct actually represents, it is difficult to accurately operationalize numeracy for the purposes of research and, furthermore, to accurately compare research findings.

Another limitation is in the choice of explanatory variables. This research did not address all variables contributing to risk comprehension skills of older Canadians. Mindful of individual characteristics such as mood, social support, personality, and cognition, (Peters et al., 2006a) as well as presentation format such as gain/loss framing, verbal vs. written, and graphical vs. text (Kreuter, 1999; Reid et al., 1994; Schapira et al., 2001) on risk comprehension ability, the investigation was purposefully limited to cancer risk comprehension and health literacy (prose and numeracy) skill. The selection of explanatory variables was a planned response to address the gaps in the research literature on health literacy, particularly numeracy skill, as it relates to risk comprehension skill. Clearly, further work is needed to explore these additional exploratory variables.

Although not part of the original research objective, data were collected on participant intention to seek colorectal cancer screening. Although the expressed intent for preventive screening is promising, these findings are based on a single self-report assessment question and the reported intention was not supported with a follow-up assessment of confirmed cases of colorectal cancer screening. Follow-up assessment

will be needed to determine whether comprehension of the educational cancer message directly influenced participant health prevention choices.

A further study limitation addresses the issue of information readability. The reading grade level of the health information in the two colorectal cancer web pages ('common and 'uncommon') was grade 10 and 11/12 reading level, respectively. Although the web page readability differs, the 95% confidence interval associated with participant total risk comprehension scores (16.8, 95% CI = 16.19, 17.38) was narrow reflecting consistency and precision in reported participant comprehension scores across both web pages. Additionally, the web page reading grade levels were higher than the grade 5/6 readability level recommended for the general public (Estey, Musseau, & Keehn, 1991). Nevertheless, participants viewed the same information that they would have obtained from naturalistic searching of the CCS website, a well-respected national cancer information source. The CCS was purposely chosen as the information source because of its highly regarded national reputation and role in cancer information dissemination.

Only two web pages were used in this study. However, these were chosen using an established list of criteria. It may be that alternative web pages would have provided significantly different comprehension results. Limiting comprehension assessment to two pages of online information was considered adequate but not arduous in terms of participant burden. Similar to the above argument, use of existing online CCS colorectal cancer information reproduces the comprehension burden that older adults would experience by independently reviewing colorectal cancer information on the online CCS site.

A final limitation relates to the classification of common and uncommon web pages. There was no confirmation that the information regarding genetic influences on colorectal cancer was unique to all study participants and it may be that some individuals had previous knowledge or experience with hereditary influences of colorectal cancer. However, accurate comprehension of the relationship between colorectal cancer and genetic make-up seems unlikely given the reported misperceptions regarding genetic influences among the public as well as healthcare professionals (Boyd et al., 2005; Lanine et al., 2004; Richards, 1996; Wideroff et al., 2005).

#### 4.4 Directions for Future Research

Development and refinement of the health literacy model and health numeracy model are crucial to research and application in this field. Research is recommended to further delineate the numeracy skill categories assessed by each of the currently used numeracy instruments (STOFHLA, general numeracy and health numeracy) (Golbeck et al., 2005b). Current numeracy instruments require further validation, and there is need for investigations into the development of additional health numeracy assessments assessing the continuum of skill rather than restricting assessment to a single numeracy skill category.

In this 'information age' of chronic disease and shared decision-making, individuals are encouraged and expected to contribute to decisions about healthcare for themselves, family members, and friends (Charles et al., 1997). Adequate health numeracy skill is a fundamental requirement for decision-making about healthcare, disease prevention, screening, diagnosis, and treatment (Gurmankin et al., 2004). Identifying consumers' and patients' strengths and weaknesses with regard to health numeracy skills may lead to the development of interventions geared to the improvement of health numeracy skills (i.e., National Institute on Aging development of tips for understanding risk).

Current findings further highlight the need for continued assessment of health numeracy skill with other groups of individuals of all ages and diseases whom for example: (1) have English as a second language, (2) use narrative communication strategies, and (3) are isolated and lack social support. An evaluation of risk comprehension and health numeracy skill is recommended for other cancer types (i.e., breast and prostate). Essentially, continued investigation is needed to further investigate the relationship between health literacy skill, particularly numeracy skill, with various age cohorts, within various chronic illnesses, and among diverse ethnic groups.

The relationship between numeracy skill and level of attained education remains intriguing. Life experience has a significant impact on the development and loss of prose and numeracy skill (Statistics Canada, 2005c). The variation of numeracy performance in older adults may reflect variation of accumulated life experience. Recognizing the importance of life long experiences, an investigation of aging and life experience with regard to prose and numeracy skill retention is recommended. The information needed to assess the collective impact of life experiences on the development of numeracy skills would require complex, longitudinal designs involving repeated cognitive assessments of the same individuals (Statistics Canada, 2005c).

It would also be interesting work to standardize numeracy skill level to mathematics grade levels as Estey et.al., (1991) have done for prose literacy skill. The recommended reading level for written health information is a grade 5/6 level. Mapping comprehension of health numeracy skill onto current mathematical education curriculums may provide a recommended numeracy skill grade level to guide the development of printed risk information for health information seekers.

This work also has potentially important practical applications in the presentation of cancer risk information and on the preparation and content of online cancer risk messages. Recognizing that even basic numeracy tasks may be perceived as more demanding if positioned with unknown vocabulary or within an unfamiliar context, information specialists and web designers are challenged to construct web-based information which allows for varying health literacy skills. This could be accomplished through the use of pop-up text boxes to define or interpret prose and numeric information in both text and audio presentation. Online information seekers may be given the choice to review 'basic', 'average', or 'advanced' content regarding a healthcare topic. As well, online health risk information could incorporate interactive images designed to explain pictorially the numeracy concept to enhance comprehension of numerical terms. All presented healthcare information benefits from plain language presentation. The use of the Internet as a presentation vehicle accommodates a continuum of information difficulty through the use of varied presentation formats (i.e., video clips, audio clips, pictures, etc.) allowing online health information seeker to take as much or as little time to review the information or to return to the information site as often as desired.

Risk communication researchers should assess how differences in culture, age, and gender affect patients' perception of risk and numeracy (Paling, 2003). Within this context, research is required to investigate how individuals actually use risk information. This would entail an understanding of the relationship between the interpretation of risk and subsequent behavioural choices (Eiser, 1998). Stated another way, researchers would essentially determine what role numeracy plays in determining individual behaviour regarding healthcare. Thus, there is a critical need for research to determine which interventions will improve cancer risk information, and result in better patient outcomes such as improved screening rates and cancer treatment (Davis et al., 2002).

#### 4.5 Conclusions

In summary, this research was an initial assessment of health literacy – prose and numeracy skill among a group of independently functioning seniors. The findings support the concept of health literacy as a collective set of prose and numeracy skills, constituting a dynamic process of learning that affects the health of individuals, and by extension, communities. Essentially, health literacy is an evolving skill that can improve or diminish depending on personal and situational variables. Experts in the fields of health and education highlight the need for concept clarification (Golbeck et al., 2005b; Steen, 2001a, 2001b). The concept of health numeracy was considered as a hierarchy of proficiency and was measured by several numeracy assessment instruments that tapped different categories of numeracy skill (Golbeck et al., 2005b; Statistics Canada, 2005c). The findings suggest that the general and health context numeracy indexes align with more abstract categories whereas STOFHLA numeracy skill is closer to the basic health numeracy category (Golbeck et al., 2005b). The numeracy skill measured by the health context numeracy scale designed by Lipkus et.al. (2001) significantly contributed to participant risk comprehension of online colorectal cancer information. Investigation of the collective use of these instruments provided a more comprehensive assessment of health numeracy skill encompassing multiple skill categories.

This research provided an assessment of risk comprehension as it was related to health literacy skill, particularly numeracy skill, among a group of community dwelling Canadian seniors. Current findings indicated that risk comprehension of online colorectal cancer information was better for common colorectal cancer information relative to uncommon risk information. Numeracy skill was a significant predictor of risk comprehension success. Participant basic numeracy skill was well developed in this group of older adults, health context numeracy skill ranked lower, and general

context numeracy skill ranked lowest in participant proficiency. As well, the IALS indicates that 50 % of Canadian adults rank below the expected proficiency minimum for numeracy skill. Taken together, this information suggests that individuals with minimal numeracy skill will not fully understand nor be able to judge the severity of potential harm associated with cancer risk messages (Statistics Canada, 2005c).

These findings have important implications regarding the relation between healthcare and education. Viewed as a social issue, health literacy extends beyond the boundaries of healthcare and the responsibility for intervening rests jointly with the educational and healthcare communities (Mika, Kelly, Price, Franquiz, & Villarreal, 2005; Nutbeam, 2000). Most formal learning institutions are designed for children and organizations of higher learning market to young adults. Given the pervasiveness of literacy in multiple societal domains (i.e., health, education, politics, workplace) the current paradigm of education needs to shift from a concerted focus on institutional education of younger generations to one that emphasizes learning throughout the lifespan. This goal may be realized through the development of programs and places of learning that accommodate the needs of all ages, including older adults.

## APPENDIX A Numeracy Assessment (Lipkus et al., 2001)

## General numeracy scale items:

- 1. Imagine that we rolled a fair, six-sided die 1,000 times. Out of 1,000 rolls, how many times do you think that die would come up even (2, 4, 6)? (Answer: 500 out of 1000)
- 2. In the Big Bucks Lottery, the chances of winning a \$10.00prize is 1%. What is your best guess about how many people would win a \$10.00 prize if 1,000 people each buy a single ticket to Big Bucks? (Answer: 10 persons out of 1000).
- 3. In the Acme Publishing Sweepstakes, the chance of winning a car is 1 in 1,000. What percent of tickets to Acme Publishing Sweepstakes win a car? (Answer: 0.1%)

## Expanded numeracy scale items:

1.	Which one of the following numbers represents the biggest risk of getting a
	disease? (Answer: 1 in 10)

- a. 1 in 100
- b. 1 in 1000
- c. 1 in 10
- 2. Which of the following numbers represents the biggest risk of getting a disease? (Answer: 10%)
  - a. 1%
  - b. 10%
  - c. 5%
- 3. If Person A's risk of getting a disease is 1% in ten years, and person B's risk of getting a disease is double that of A's, what is B's risk? (Answer: 2%)
- 4. If Person A's chance of getting a disease is 1 in 100 in ten years, and person B's risk is double that of A's, what is B's risk? (Answer: 2 out of 100)
- 5. If the chance of getting a disease is 10%, how many people would be expected to get the disease?
  - A: Out of 100? (Answer: 10)
  - B: Out of 1000? (Answer: 100)
- 6. If the chance of getting a disease is 20 out of 100, this would be the same as having a \_\_\_\_\_\_ % chance of getting the disease. (Answer: 20)
- 7. The chance of getting a viral infection is .0005. Out of 10,000 people, about how many of them are expected to get infected? (Answer: 5 people)

### APPENDIX B

## The Newest Vital Sign

**NVS** Assessment Questions

Read to Subject: This information is on the back of a container of a pint of ice cream.

### Questions

- 1. If you eat the entire container, how many calories will you eat? (Answer: 1,000)
- 2. If you are allowed to eat 60 g of carbohydrates as a snack, how much ice cream could you have? (Answer: 1 cup or half the container)
- 3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes 1 serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day? (Answer: 33 g)
- 4. If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving? (Answer: 10%)
- 5. Is it safe for you to eat this ice cream? (Answer: No)
- 6. (Ask only if the patient responds "no" to question 5): Why not? (Answer: Because it has peanut oil).

## APPENDIX C CCS Colorectal Cancer 'Common' and 'Uncommon' Web Pages

## Canadian Cancer Encyclopedia™ - Colorectal Cancer

### **Statistics**

Currently, colorectal cancer is the 4th most commonly diagnosed cancer and the 2nd leading cause of cancer death in Canada. The most recent estimated statistics for colorectal cancer for 2005 are:

- 19.600 new cases
- 8,400 deaths

### Incidence

Incidence is the number of new cases of a particular type of cancer diagnosed each year. Actual numbers take some years to establish, so current statistics are always estimates.

## Estimated new cases of colorectal cancer in Canada, 2005

All Canadians	19,600
Men	10,600
Women	9,000

## Lifetime probability of developing colorectal cancer

Men	1 in 14
Women	1 in 16

### Mortality

Mortality is the number of deaths due to a particular type of cancer each year. Actual numbers take some years to establish, so current statistics are always estimates.

### Estimated colorectal cancer deaths in Canada, 2005

All Canadians	8,400
Men	4,500
Women	3,900

## Lifetime probability of dying from colorectal cancer

Men	1 in 28
Women	1 in 31

**Note:** For 2005 the population of Canada is estimated to be 31,949,000. For more information, go to Canadian Cancer Statistics.

#### **GENETICS**

Genetic risk factors are altered or damaged genes that may increase the risk of developing certain types of cancer. The genetic risk factors for colorectal cancer are:

## Familial Adenomatous Polyposis (FAP)

Also known as familial polyposis, FAP is a rare, inherited (genetic) condition occurring in about 1 in 8000 people, that causes large numbers of tissue lumps (polyps) to develop on the inner bowel lining. Most polyps are non-cancerous (benign), but some have the potential to become cancerous (malignant). FAP accounts for 1% of all colorectal cancers. People with FAP are almost certain to develop colorectal cancer.

Since people with FAP may develop cancers in adolescence, screening should begin between the ages of 10-12. First-degree family members (parents, sibling or children) of people with FAP should be screened as well.

Most cases of FAP are due to alterations of the adenomatous polyposis coli (APC) gene.

## **Other Polyposis Syndromes**

Other syndromes characterized by very large numbers of polyps (polyposis syndromes) and associated with a high risk of colorectal cancer include:

- Peutz Jeahers syndrome
- Gardner's syndrome
- Turcot's syndrome
- juvenile polyposis.

### Hereditary Nonpolyposis Colorectal Carcinoma (HNPCC)

Also known as Lynch syndrome or cancer family syndrome, HNPCC is another uncommon, genetic condition that may lead to colorectal cancer. It is believed to account for 3-5% of all colorectal cancers. Polyps are present but do not occur in large numbers. People with this syndrome have an estimated 70% lifetime risk of developing colorectal cancer, usually in the part of the colon closest to the small intestine (proximal colon).

The main features (Amsterdam Criteria) of this syndrome are:

- three or more relatives with an HNPCC-associated cancer one being a first-degree relative of the other two
- one or more family members diagnosed with colorectal cancer before 50
- relatives in at least two successive generations affected by HNPCC

There are two syndromes of HNPCC:

- Type A (Lynch 1)
- Type B (Lynch 2)

People with Type A have an increased risk for colon cancer. People with Type B syndrome have an increased risk for early onset of cancers of the:

- colon
- ovaries
- endometrius
- breast
- pancreas
- stomach
- small intestine
- kidney
- renal pelvis
- ureter

Genetic studies have so far found six genes that, when altered, lead to the development of HNPCC. The most clinically important of these appear to be: hMSH2, hMLH1, hPMS1, and hPMS2.

#### Inherited Colorectal Cancer In Ashkenazi Jews

Ashkenazi Jewish families have been found to be at higher risk for colorectal cancer than other ethnic groups, perhaps because of a mutation in the APC 1307 gene.

For help 2002-2004 Canadian Cancer Society. finding All rights reserved, Legal Privacy information on cancer, please call our information specialists toll-free at 1 888 939-3333 Monday to Friday, a.m. to 6 p.m., anywhere in Canada.

## APPENDIX D Comprehension Questions for Canadian Cancer Society General Web Pages

**Instructions:** 

Please circle the best answer for the multiple-choice questions. Space is provided for the short answer questions to respond to each question. Please refer as often as needed to the given web page.

1) Colo	orectal cancer is the	most diagnosed type of cancer.
a)	First	
b)	Second	
c)	Third	
d)	Fourth	
e)	Do not know	
-		he number of cancer deaths.
,	Greatest	
	Second greatest	
	Third greatest	
	Fourth greatest	
e) ]	Do not know	
3) How	w many new cases of c	olorectal cancer were diagnosed in the year 2005?
	19,600	
	10,400	
	8,800	
	8,300	
e)	Do not know	
4) How	w many of the new cas	es in the year 2005 were men?
a)	19,600	
b)	10,600	
c) 8	8,800	
d)	8,300	
e) ]	Do not know	
5) Wha	nt does incidence mean	n?
a)	The total number o	f new cancer cases diagnosed each year
b)	The total number of	cancer cases in Canada
c)	The total number of	cancer survivors
d)	The total number of	cancer deaths
	Do not know	
6) Wha	at is the mortality rate	for women in 2005?
a)	19,600	
b)	8,400	
c)	8,300	
4)	3 900	

e) Do not know

- 7) Over the course of a lifetime, what is the risk of death from colorectal cancer for men?
  - a) 1 in 14
  - b) 1 in 15
  - c) 1 in 28
  - d) 1 in 31
  - e) Do not know
- 8) Using the given incidence rates, how would you figure out the incidence of 'All Canadians' if this value were not given in the table? Please explain briefly.
- 9) The number of deaths from colorectal cancer in the year 2005 is 8,400. The number of men who died during the year 2005 was 4,500. What percentage of men died during the year 2005?
  - a) 46%
  - b) 54%
  - c) 29%
  - d) 63%
  - e) Do not know
- 10) Which gender (men or women) has the greater risk of dying?
  - a) Men
  - b) Women
  - c) Do not know
- 11) Knowing that the lifetime probability of developing colorectal cancer is 1 in 16 for women, in your opinion, what level of risk does this represent?
  - a) High risk
  - b) Moderate risk
  - c) Low risk
- 12) Would you seek screening for colorectal cancer knowing that your lifetime risk is 1 in 14 for men and 1 in 16 for women?
  - a) Yes
  - b) No
  - c) Unsure

If you answer 'No' or unsure, indicate what lifetime risk would persuade you to seek screening and explain why.

If you answer 'Yes", indicate what lifetime risk would persuade you NOT to seek screening and explain why.

13) The percentage of deaths from colorectal cancer in 2005 for all Canadians is 0.02% and the percentage of new cases in 2005 among all Canadians is 0.06%. Are there more people developing colorectal cancer than there are people dying from it?

- a) Yes
- b) No
- c) Do not know

## Comprehension Questions for Canadian Cancer Society Genetics and Colorectal Cancer Web Page

#### **Instructions:**

Please circle the best answer for the multiple-choice questions. Space is provided for the short answer questions to respond to each question. Please refer as often as needed to the given web page.

- 1) Human genes are found in all cells of the body. Genes are vital because:
  - a) They hold crucial information passed on only from the mother
  - b) They are the cause of all disease
  - c) They instruct the cell about what it should do and how it should function
  - d) They protect us from disease
  - e) Do not know
- 2) If you have damaged genes:
  - a) You will always form some type of cancer
  - b) You may have an increased risk of forming certain types of cancer
  - c) Genetic tests will provide 100% confirmation whether or not you will develop cancer
  - d) You never have to worry about getting cancer
  - e) Do not know
- 3) Please list 2 of the genetic risk factors for colorectal cancer.
- 4) Polyps are lumps of tissue that can form on the inner lining of the bowel. It is best to detect polyps early because:
  - a) They will always turn into colorectal cancer
  - b) Some might be benign and will turn into colorectal cancer
  - c) Some might be malignant and will turn into colorectal cancer
  - d) Polyps protect against cancer
  - e) Do not know
- 5) Familial Polyposis is rare. If you have this:
  - a) You will never form polyps
  - b) The chance of getting colorectal cancer is low
  - c) The chance of getting colorectal cancer is very high
  - d) The chance of getting colorectal cancer is greatest in seniors
  - e) Do not know

- 6) Refer to the web page for examples of what is meant by 'first-degree' family members. List the examples you find.
- 7) The web page states that Familial Polyposis is rare. What is the number used to define 'rare'?
- 8) Familial Polyposis accounts for 1% of all colorectal cancers. If the total of number of all cases equaled 10,000 how many cases would result from this?
  - a) 10
  - b) 0.1
  - c) 100
  - d) 0.01
  - e) Do not know
- 9) Lynch Syndrome is believed to account for 3% to 5% of all colorectal cancer cases. So of all the people with colorectal cancer, this syndrome accounts for of the cases.
  - a) Almost all
  - b) None
  - c) Half
  - d) Very few
  - e) Do not know
- 10) Are people with Familial Polyposis or people with Lynch Syndrome more likely to form colorectal cancer?
  - a) Familial Polyposis
  - b) Lynch Syndrome
- 11) There are 'other risk factors' (e.g. diet) for colorectal cancer as well as genetic risk factors. The web page states that Familial Polyposis accounts for 1% of all cases and Lynch Syndrome accounts for 3% to 5% of all cases. Let's assume that all other colorectal cancer cases are caused by 'other risk factors'. Put in order from least to greatest, how each of these three things ('other risk factors', Familial Polyposis, Lynch Syndrome) contribute to the development of colorectal cancer.

Least	FAP
_	Lynch Syndrome
Greatest _	Other risk factors
<b>↓</b>	

12) Ashkenazi Jews are at 'higher risk' for colorectal cancer than other ethnic groups. **In your own words**, explain what this means and suggest a number out of 100 that defines 'higher risk' in your opinion.

## APPENDIX E Introductory Research Letter



University of Waterloo 200 University Avenue West Waterloo, Ontario, Canada N2L 3G1

#### Dear

This letter is an invitation to consider participating in a study I am conducting as part of my PhD degree in the department of Health Studies and Gerontology at the University of Waterloo under the supervision of Dr. Laurie Hoffman-Goetz and Dr. Jose Arocha. I would like to provide you with more information about this project and what your involvement would entail if you decide to take part.

As people are trying to make decisions regarding their healthcare, more and more are searching for information on the Internet to either supplement information obtained from healthcare professionals or to ensure that all healthcare choices have been accurately considered. It is important that information entailed in decision making is clearly understood allowing individuals to make informed decisions about their healthcare. Therefore this study intends to examine individuals' comprehension of online cancer information.

Participation in the study is completely voluntary. Approximately, one hundred individuals, men and women, 50 years of age and older and able to read and write in English, will be invited to participate. If you choose to participate, you will be asked to take part in one session scheduled at a mutually convenient time. This includes a personal interview asking general questions about yourself, and specific questions regarding healthcare information. As well, you will be asked to read two pages of information on cancer taken from the Canadian Cancer Society website. You will then be asked questions concerning the information within these two web pages. You will be asked for verbal comments and feedback on the cancer information from the Internet and this information will be audiotaped. The entire session should take approximately 1 ½ hours. You may decline to answer any of the questions if you so wish. Further, you may decide to withdraw from this study at any time without negative consequences by advising the researcher. All information is considered completely confidential. Your name will not appear in any thesis or report resulting from this study. In fact, the information you provide will be pooled with information from all other participants. Data collected during this study will be retained for 4 years in a locked office in my supervisor's lab. Only researchers associated with this project will have access.

The anticipated risk to participants is negligible. You may find it difficult to read about cancer if you know someone who has experienced this disease. However, you are free to withdraw from the study at any time without any penalty. Personal benefits include increased knowledge regarding cancer prevention. Additionally, you will be contributing to an understanding of the usefulness of cancer care information on the

Internet in enabling individuals to make informed decisions. Your participation will also contribute to improving the quality of information on the Internet.

In appreciation of your contribution, you will receive a stipend of \$40.00. As a volunteer, you may decide to withdraw from this study, without consequence, at any time by advising the researcher.

If you have any questions regarding this study, or would prefer additional information to assist you in reaching a decision about participating, please contact me at (519) 888-4567 ext. 6018 or by email at <a href="mailto:ldonelle@ahsmail.uwaterloo.ca">ldonelle@ahsmail.uwaterloo.ca</a>. Please feel free to contact either faculty investigators, Dr. Laurie Hoffman-Goetz at (519) 888-4567 ext. 3098 or by email at <a href="mailto:lhgoetz@healthy.uwaterloo.ca">lhgoetz@healthy.uwaterloo.ca</a> or Dr. Jose Arocha at (519) 888-4567 ext. 2729 or by email at <a href="mailto:jfarocha@healthy.uwaterloo.ca">jfarocha@healthy.uwaterloo.ca</a>. However, the final decision is yours.

Please be assured that this study has been reviewed and has received ethics clearance through the Office of Ethics Research at the University of Waterloo. If you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes or this office at (519) 888-4567 ext. 6005.

I look forward to speaking to you further regarding this project and thank you in advance for your assistance in this regard.

Respectfully yours,

Lorie Donelle BScN., M.A., PhD candidate Health Studies and Gerontology, University of Waterloo (519) 888-4567 ext.6018

email: Idonelle@ahsmail.uwaterloo.ca

## **APPENDIX F Consent Form**

#### **CONSENT FORM**

I have read the information presented in the information letter about a study being conducted by Lorie Donelle of the Department of Health Studies and Gerontology at the University of Waterloo supervised by Dr. Laurie Hoffman-Goetz and Dr. Jose Arocha. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

As part of this study, I agree to participate in one session consisting of: (1) general question and answers regarding comprehension of health information, and (2) reading, responding to, and commenting on information contained in two different articles on cancer information from the Internet. I understand that my comments regarding the cancer information articles will be audiotaped in order to establish an accurate record of my thoughts and observations of this Internet based information.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through the Office of Research Ethics at the University of Waterloo. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director at the Office of Research Ethics at (519) 888-4567 ext. 6005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

YES	
NO	
Participant Name:	(please print)
Participant Address:	
Participant Signature:	
Witness Name:	(please print)
Witness Signature:	
Date:	

## APPENDIX G Recruitment Poster

## **Department of Health Studies and Gerontology**

**University of Waterloo** 

## PARTICIPANTS NEEDED FOR RESEARCH IN HEALTH EDUCATION



We are looking for volunteers to take part in a study of *participant understanding of cancer information*.

Eligibility: 50+ years of age and can read and write in English. You will be asked to respond to a confidential questionnaire and to information from the Canadian Cancer Society.

In appreciation for your time, you will receive **\$40.00** 

For more information about this study, or to volunteer for this study, please contact:

## L. Donelle 519-888-4567 Ext. 6018 or Email: Idonelle@ahsmail.uwaterloo.ca

This study has been reviewed by, and received ethics clearance through, the Office of Research Ethics, University of Waterloo.

888.	888	888.	888	888.	888	888-	888-	888-	888-	888-
ext.	ext.	ext.	ext.	ext.	ext	ext. (	ext.	ext.	ext.	ext.
.4567	-4567	-4567	888-4567	-4567	888-4567	.4567	-4567	-4567	-4567	-4567
.6018	6018	6018	ext. 6018	6018	ext. 6018	.6018	. 6018	. 6018	. 6018	. 6018

# APPENDIX H General Demographic Questionnaire

1)	Age: a) Under 50 years b) 50-59 c) 60-69 d) 70-79 e) 80+
2)	Gender: a) Male b) Female
3)	Marital Status:  a) Single / never married  b) Married  c) Separated  d) Divorced  e) Widowed  f) Other
4)	Employment:  a) Full-time b) Part-time c) Retired d) Not employed
5)	List your current and previous occupation. If retired or not employed list your previous 2 occupations:  a) b)
6)	Estimated Income (from all sources):  a) Less than \$14,999  b) \$15,000 to \$34,999  c) \$35,000 to \$54,999  d) \$55,000 to \$74,999  e) \$75,000 to \$99,999  f) More than \$100,000
7)	Education:  a) Elementary school (grade 8 or less) b) Some high school c) High school diploma d) College / Trade diploma e) Some university f) Bachelor's degree g) Graduate degree h) Other: Please specify:

	any educational courses you have taken within the past 5 years for either
	ess or personal reasons.
a	· —————————
b	, <del></del>
C	
d	· ————
e	)
9) List t	he hobbies that you are involved in:
a	
	)
c	· ————
	)
e	
10) List a	any volunteer positions that you hold:
-	)
b	
c	, <del></del>
d	
e	
<b>-</b>	,
11) Were	you born in Canada?
	Yes
b	) No
10) D :	1 1 1 2
	ary language spoken at home?
	) English
	) French
c	) Other:
12) D. C	
	rred language for cancer information:
	) English
	) French
c	) Other:
	e list any other languages spoken:
b	)
15) Pleas	e list any other languages used for reading:
a	
b	)
16) Harri	would you describe your chility to mad information pointed in Eq. 114.6
	would you describe your ability to read information printed in English?
	) Excellent
b	) Very good

- c) Good
- d) Fair
- e) Poor
- 17) Please indicate how often you read an English language newspaper during the last 12 months.
  - a) Daily
  - b) At least 3 times a week
  - c) At least once a month
  - d) Less than once a month
- 18) Please indicate how often you read an English language magazine during the last 12 months.
  - a) At least once a week
  - b) At least once a month
  - c) 5 or more times a year, but not every month
  - d) 1 to 4 times a year
- 19) Please indicate how often you read a book (printed in English) during the last 12 months.
  - a) At least a book a week
  - b) At least a book a month
  - c) At least a book every 3 months
  - d) At least a book every 6 months
  - e) At least a book a year
- 20) Please indicate how you would describe your ability to understand numerical/statistical information.
  - a) Excellent
  - b) Very good
  - c) Good
  - d) Fair
  - e) Poor
- 21) What is your preferred media source for cancer information?
  - a) Television
  - b) Radio
  - c) Magazines
  - d) Newspapers
  - e) Pamphlets / Brochures
  - f) Internet
  - g) Other: Please specify:\_\_\_\_\_
- 22) Do you own a computer?
  - a) YES
  - b) NO

a)	YES
b)	NO
	e do you use the Internet?
,	Home
	Work
	Home and work
	Library
	Community Centre
1)	Other: Please specify:
25) How o	ften do you search the Internet for cancer information?
	Never
/	One time per week
	More than one time per week
	One time per month
	Other: Please specify:
26) What t	ype of cancer do you search for information about?
a)	Breast
b)	Colorectal
c)	Prostate
d)	Lung
e)	Other: Please specify:
27) When yon:	you search for cancer information, do you usually look for information
a)	General prevention strategies (for example, nutrition, exercise)
b)	
	mammograms)
	Treatment choices (for example, medication, surgery)
d)	Staging of cancer (for example, progression of disease)
e)	Other: Please specify:
f)	None

23) Do you have access to the Internet?

#### APPENDIX I

### Functional Health Literacy (Prose / Numeracy) Assessment: STOFHLA

The STOFHLA consists of a reading comprehension section containing 2 prose passages that are derived from realistic healthcare episodes: (1) preparation for upper gastrointestinal testing and (2) understanding consumer rights and responsibilities in applying for Medicaid. The readability levels of the 2 passages as measured by the Gunning Fog Index are equivalent to grades 4 and 10 respectively (Baker et al., 1999). In total there are 36 Cloze items that measure an individual's ability to read. Each of the 36 items of the reading comprehension section are assigned a score of 2 for a maximum score of 72 points.

The S-TOFHLA also contains 4 numeracy items that assess an individual's ability to understand numbers within the context of healthcare. Numeracy test questions assess comprehension of prescribed drug dosages, monitoring blood glucose, and scheduling clinic appointments. Cue cards or labeled prescription bottles are presented to the consumer who then responds to questions that are posed orally from the test administrator. Each of the 4 numeracy items is assigned a score of 7 points for a possible 28 total points.

As with the TOFHLA, the S-TOFHLA has a combined total score ranging from 0 to 100. Individuals scoring 0 to 53 fall within the inadequate health literacy category. Those scoring 54 to 66 are considered marginally health literate, and scores ranging from 67 to 100 represent adequate health literacy. The maximum time for test administration is 12 minutes. The S-TOFHLA shows adequate internal consistency (Cronbach's alph = 0.68) for the numeracy items and good internal consistency (Cronbach's alpha = 0.97) for reading comprehension. The correlation was also good

between the S-TOFHLA and the REALM at 0.80 (Baker et al., 1999). The S-TOFHLA is reliable and valid relative to the TOFHLA but with increased practicality.

## Reading Comprehension and Numeracy Examples in STOFHLA

## Reading Comprehension Passage A Your doctor has sent you to have a \_\_\_\_\_ x-ray. (a) stomach (b) diabetes (3) stitches (4) germs You must have an \_\_\_\_\_\_ stomach when you come for \_\_\_\_\_. (a) asthma (b) empty (c) incest (d) anemia (a) is (b) am (c) if (d) it The X-ray will\_\_\_\_\_\_from 1 to 3 \_\_\_\_\_\_ to do. (a) take (b) view (c) talk (d)look (a) beds (b) brains (c) hours (d) diets The DAY BEFORE THE X-RAY For supper have only a \_\_\_\_\_snack of fruit, \_\_\_\_and jelly, with coffee or tea. (a) little (b) broth (c) attack (d) nausea (a)toes (b) throat (c) toast (d) thigh **Numeracy Item 1 (Label on prescription bottle)** Take one tablet by mouth 6 hours as needed. Oral Question: if you take your first tablet at 7:00am, when should you take the next one? Correct Answer: 1:00pm. **Numeracy Item 2 (Prompt card)** Normal blood sugar is 60-150. Your blood sugar today is 160. Oral Question: If this were your score, would your blood sugar be normal today? Correct Answer: No

## **Numeracy Item 3 (Prompt card)**

**Clinic Appointment** 

Clinic: Diabetic Location: 3<sup>rd</sup> floor

Day: Thurs. Date: April 2<sup>nd</sup> Hour: 10:20

Issued by:

You must bring your plastic card with you

Oral Question: When is your next appointment? Correct Answer: April  $2^{nd}$  or Thursday April  $2^{nd}$ 

## APPENDIX J General Context Numeracy Assessment

This instrument captures one's ability to utilize quantitative information as related to competence with basic probability and numerical concepts (Schwartz et al., 1997). The first question assesses familiarity with the concept of probability, the second assesses ability to convert percentage (1%) to proportion (10 in 1000) and the third assesses the reverse calculation with conversion of a proportion (1 in 1000) to percentage (0.1%) (Schwartz et al., 1997). Participant score is based on the number of questions answered correctly with scores ranging from 0 (no correct answers) to 3 (all questions answered correctly). All general numeracy questions are found below:

"Imagine that we flip a fair coin 1,000 times. What is your best guess about how many times the coin would come up heads in 1,000 flips? Answer: 500

"In the Big Bucks Lottery, the chance of winning a \$10 prize is 1%. What is your best guess about how many people would win a \$10 prize if 1000 people each buy a single ticket to Big Bucks"? Answer: 10

"In Acme Publishing Sweepstakes, the chance of winning a car is 1 in 1,000. What percent of tickets to Acme Publishing Sweepstakes win a car? Answer: 0.1%

## APPENDIX K **Health Context Numeracy Assessment**

A eight item 'expanded' numeracy questionnaire framed risk / probability questions within the context of health (Lipkus et al., 2001). These questions were developed to mimic the same or similar mathematical operations incorporated into the 3-question probability instrument described above. Researchers concentrated on probabilities, proportions, and percentages because of their widespread use in educational risk communication materials, decision aids, and clinical risk conversations. The numeracy questions contextualized within a healthcare setting include:

Which one of the following numbers represents the biggest risk of getting a disease?

1 in 100

1 in 1000

1 in 10

Answer: 1 in 10

Which of the following numbers represents the biggest risk of getting a disease?

1%

10%

5%

Answer: 10%

If Person A's risk of getting a disease is 1% in ten years, and person B's risk of getting a disease is double that of A's, what is B's risk?

Answer: 2%

If Person A's chance of getting a disease is 1 in 100 in ten years, and person B's risk is double that of A's, what is B's risk?

Answer: 2 out of 100

If the chance of getting a disease is 10%, how many people would be expected to get the disease?

A: Out of 100? Answer: 10

B: Out of 1000? Answer: 100

If the chance of getting a disease is 20 out of 100, this would be the same as having a \_\_\_\_20\_\_\_\_ % chance of getting the disease.

The chance of getting a viral infection is .0005. Out of 10,000 people, about how many of them are expected to get infected? Answer: 5

## APPENDIX L Math Anxiety Assessment

The Abbreviated Math Anxiety Scale (AMAS) was developed from the Math Anxiety Rating Scale (MARS) and the revised version MARS –R (Hopko et al., 2003a). The AMAS is a 9-item scale with strong internal consistency ( $\alpha$  = .90) and test-retest reliability (r = .85) (Hopko et al., 2003a). There is also strong convergent validity between the AMAS and the MARS-R. Test items are formatted using a Likert type scale with responses ranging from 1 (low anxiety) to 5 (high anxiety) with a possible composite score of 45. A factor analysis revealed the existence of two subscales: (1) Learning Math Anxiety (LMA), and (2) Math Evaluation Anxiety. The test requires participants to indicate their anxiety level, using a scale of 1 to 5, in situations where they would "have to use the tables in the back of a math book", "Listen to a lecture in math class" or "Listen to another student explain a math formula" (Hopko et al., 2003a). The AMAS has been identified as superior to the MARS-R as a measurement of mathematics anxiety (Hopko et al., 2003a). Total MAR-S scores will be used to represent participant math anxiety. The full MAR-S scale follows:

For the following statements, please rate each item in terms of how anxious you would feel during the event specified. Use the following scale and record your answer in the space to the left of the item:

## Scale:

- 1 = Low Anxiety
- 2 = Some Anxiety
- 3 = Moderate Anxiety
- **4 = Quite a bit of Anxiety**
- 5 = High Anxiety

1. Having to use the tables in the back of a math book.
2. Thinking about an upcoming math test one day before.
 _ 3. Watching a teacher work an algebraic equation on the blackboard.
4. Taking an examination in a math course.

	problems which is due the next class meeting.
6. ]	Listening to a lecture in math class.
7. ]	Listening to another student explain a math formula.
8. ]	Being given a "pop" quiz in a math class.
9. 3	Starting a new chapter in a math book.

## APPENDIX M Numeracy Assessment (Estrada et al., 2004)

"Imagine that we flip a fair coin 1,000 times. What is your best guess about how many times the coin would come up heads in 1,000 flips?

Answer: 500

"In the Big Bucks Lottery, the chance of winning a \$10 prize is 1%. What is your best guess about how many people would win a \$10 prize if 1000 people each buy a single ticket to Big Bucks"?

Answer: 10

"In Acme Publishing Sweepstakes, the chance of winning a car is 1 in 1,000. What percent of tickets to Acme Publishing Sweepstakes win a car?

Answer: 0.1 %

"If you have 5 mg pills of Coumadin and you take 7.5 mg a day, how many of those pills should you take every day?

Anwer: 1.5 pills

"If you have 5mg pills of Coumadin and you take 7.5mg a day. If you have 9 pills left, you would have enough for one week? Yes/No

Answer: No

"Your normal INR should be 2 to 3. If your INR today is 3.5, would your INR be: Low/Normal/High

Answer: High

# APPENDIX N Representative Statistics

## **Chapter 2: Numeracy Assessment**

The Correlational Relationship Among Numeracy Assessment Tools: The Test of Functional Health Literacy for Adults (S-TOFHLA), General Numeracy and Health Numeracy Instruments

#### Correlations

			General Numeracy total score	Health Numeracy total score
Spearman's rho	General Numeracy	Correlation Coefficient	1.000	.488**
	total score	Sig. (2-tailed)		.000
		N	140	140
	Health Numeracy	Correlation Coefficient	.488**	1.000
	total score	Sig. (2-tailed)	.000	
		N	140	140

<sup>\*\*</sup> Correlation is significant at the 0.01 level (2-tailed).

## Correlations

			Health Numeracy total score	SFHL prose numeracy total score
Spearman's rho	Health Numeracy	Correlation Coefficient	1.000	.426**
	total score	Sig. (2-tailed)		.000
		N	140	140
	SFHL prose	Correlation Coefficient	.426**	1.000
	numeracy total score	Sig. (2-tailed)	.000	
		N	140	140

<sup>\*\*.</sup> Correlation is significant at the 0.01 level (2-tailed).

#### **Correlations**

			SFHL prose numeracy total score	General Numeracy total score
Spearman's rho	SFHL prose	Correlation Coefficient	1.000	.258**
	numeracy total score	Sig. (2-tailed)	-	.002
		N	140	140
	General Numeracy	Correlation Coefficient	.258**	1.000
	total score	Sig. (2-tailed)	.002	
		N	140	140

<sup>\*\*</sup> Correlation is significant at the 0.01 level (2-tailed).

# Logistic Regression (Prose health literacy, math anxiety, and attained education regressed on General Numeracy Scores)

## **Categorical Variables Codings**

				Paramete	er coding	
		Frequency	(1)	(2)	(3)	(4)
Revised	grade 8 or less	9	1.000	.000	.000	.000
Education	some high school	19	.000	1.000	.000	.000
Scores	high school diploma	24	.000	.000	1.000	.000
	trade/college/some university/bachelors degree	73	.000	.000	.000	1.000
	graduate degree	11	.000	.000	.000	.000
participant	male	35	1.000			
gender	female	101	.000			

## **Case Processing Summary**

Unweighted Cases	N	Percent	
Selected Cases	Included in Analysis	136	97.1
	Missing Cases	4	2.9
	Total	140	100.0
Unselected Cases		0	.0
Total		140	100.0

a. If weight is in effect, see classification table for the total number of cases.

## **Omnibus Tests of Model Coefficients**

		Chi-square	df	Sig.
Step 1	Step	33.684	6	.000
	Block	33.684	6	.000
	Model	43.178	7	.000

## **Model Summary**

	-2 Log	Cox & Snell	Nagelkerke
Step	likelihood	R Square	R Square
1	144.622 <sup>a</sup>	.272	.363

a. Estimation terminated at iteration number 5 because parameter estimates changed by less than .001.

## Classification Table<sup>a</sup>

				Predicted	
				_	
			GenNur	neracy2	Percentage
	Observed		0-1 score	2-3 score	Correct
Step 1	GenNumeracy2	0-1 score	57	16	78.1
		2-3 score	16	47	74.6
	Overall Percentage				76.5

a. The cut value is .500

## Variables in the Equation

								95.0% C.I.1	for EXP(B)
		В	S.E.	Wald	df	Sig.	Exp(B)	Lower	Upper
Step	Gender2(1)	.695	.484	2.061	1	.151	2.003	.776	5.172
1	ReviseEduc			8.496	4	.075			
	ReviseEduc(1)	-1.295	1.194	1.176	1	.278	.274	.026	2.844
	ReviseEduc(2)	-2.050	1.148	3.191	1	.074	.129	.014	1.221
	ReviseEduc(3)	-1.000	.878	1.298	1	.255	.368	.066	2.056
	ReviseEduc(4)	003	.790	.000	1	.997	.997	.212	4.690
	Mathanxtot	101	.029	11.956	1	.001	.904	.853	.957
	SFHLprose	.008	.022	.141	1	.708	1.008	.966	1.053
	Constant	1.964	1.890	1.081	1	.299	7.130		

a. Variable(s) entered on step 1: ReviseEduc, Mathanxtot, SFHLprose.

## Regression Modeling of Health Numeracy (Prose health literacy, math anxiety, and attained education regressed on Health Numeracy Scores)

## Variables Entered/Removed

Model	Variables Entered	Variables Removed	Method
1	participant gender(a)		Enter
2	SFHLprose, Math anxiety total score, Revised Education Scores(a)		Enter

a All requested variables entered.b Dependent Variable: Health Numeracy total score

## Model Summary(c)

						Cha	ange Sta	tistics	
Mo		R Squar	Adjust ed R Squar	Std. Error of the Estimat	R Squar e Chan	F Chan			Sig. F
del	R	e	. е	е	ge	ge	df1	df2	Change
1	.264( a)	.070	.063	1.8952 1	.070	10.01 2	1	134	.002
2	.508( b)	.258	.235	1.7117 3	.188	11.08 8	3	131	.000

a Predictors: (Constant), participant gender

## ANOVA(c)

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	35.962	1	35.962	10.012	.002(a)
	Residual	481.303	134	3.592		
	Total	517.265	135			
2	Regression	133.431	4	33.358	11.385	.000(b)
	Residual	383.834	131	2.930		
	Total	517.265	135			

a Predictors: (Constant), participant gender

## Coefficients(a)

Мо		Unstand d Coef		Standar dized Coefficie nts			95% Col Interva Lower	nfidence al for B Upper
del		В	Error	Beta	t	Sig.	Bound	Bound
1	(Constant)	6.800	.320		21.22 7	.000	6.166	7.434
	participant gender	- 1.176	.372	264	- 3.164	.002	-1.911	441
2	(Constant)	2.891	1.062		2.721	.007	.789	4.993
	participant gender	835	.351	187	2.379	.019	-1.530	141
	Revised Education Scores	.542	.165	.289	3.296	.001	.217	.868
	Math anxiety total score	006	.019	025	306	.760	043	.032
	SFHLprose	.039	.015	.216	2.543	.012	.009	.069

a Dependent Variable: Health Numeracy total score

b Predictors: (Constant), participant gender, SFHLprose, Math anxiety total score, Revised Education Scores

c Dependent Variable: Health Numeracy total score

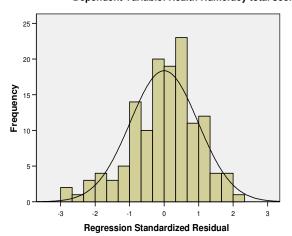
b Predictors: (Constant), participant gender, SFHLprose, Math anxiety total score, Revised Education Scores

c Dependent Variable: Health Numeracy total score

## **Regression Model Sample Residual Graphs**

## Histogram

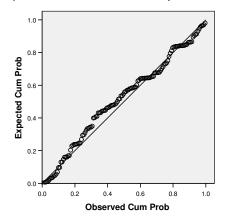
## Dependent Variable: Health Numeracy total score



Mean =1.08E-17□ Std. Dev. =0.985□ N =136

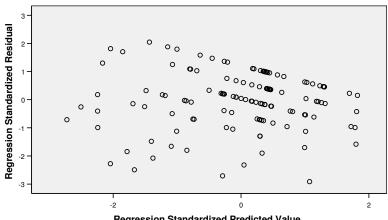
#### Normal P-P Plot of Regression Standardized Residual

## Dependent Variable: Health Numeracy total score



Scatterplot

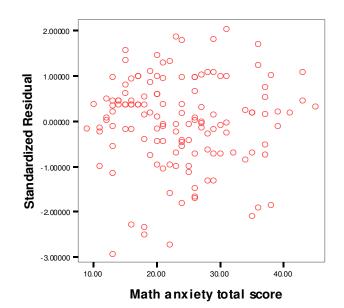
Dependent Variable: Health Numeracy total score



**Regression Standardized Predicted Value** 

**Scatterplot** 

## **Dependent Variable: Health Numeracy Score**



# Regression Modeling of Moderation Effect: Influence of Math Anxiety and Formal Education on Health Numeracy Skill

Dependent Variable: Health Numeracy total score

Parameter	В	Std. Error	t	Sig.	95% Confide Lower Bound	ence Interval Upper Bound
Intercept	2.912	1.352	2.155	.033	.239	5.586
ReviseEduc	1.392	.488	2.851	.005	.426	2.358
Mathanxtot	.043	.050	.873	.384	055	.142
ReviseEduc * Mathanxtot	025	.019	-1.337	.184	063	.012

a Computed using alpha = .05

## **Chapter 3: Risk Comprehension**

## Skill Differences Between Common and Uncommon Risk Comprehension Scores

(Wilcoxon Signed Ranks Test)

## **Descriptive Statistics**

	N	Mean	Std. Deviation	Minimum	Maximum
General Comprehension total score	140	9.14	1.749	2	11
Specific Comprehension total score	140	7.6429	2.33852	.00	11.00

## Ranks

		N	Mean Rank	Sum of Ranks
Specific Comprehension	Negative Ranks	100 <sup>a</sup>	60.85	6085.00
total score - General	Positive Ranks	17 <sup>b</sup>	48.12	818.00
Comprehension total	Ties	23 <sup>c</sup>		
score	Total	140		

a. Specific Comprehension total score < General Comprehension total score

b. Specific Comprehension total score > General Comprehension total score

C. Specific Comprehension total score = General Comprehension total score

Test Statistics<sup>b</sup>

	Specific Comprehensi on total score - General
	Comprehensi
	on total score
Z	-7.248 <sup>a</sup>
Asymp. Sig. (2-tailed)	.000

a. Based on positive ranks.

# Total Risk Comprehension Regression Model A Priori Explanatory Variables

## **Descriptive Statistics**

	Mean	Std. Deviation	N
Total Comprehension score general and specific	16.8676	3.52517	136
participant gender	.74	.439	136
Revised Education Scores	2.4265	1.04444	136
SFHL numeracy total score	26.2500	3.68932	136
Math anxiety total score	23.6544	8.25912	136
Health Numeracy total score	5.9265	1.95744	136
General Numeracy total score	1.3750	1.04660	136
SFHLprose	64.1471	10.95616	136

b. Wilcoxon Signed Ranks Test

## **ANOVA<sup>c</sup>**

		Sum of				
Model		Squares	df	Mean Square	F	Sig.
1	Regression	36.100	1	36.100	2.947	.088 <sup>a</sup>
	Residual	1641.517	134	12.250		
	Total	1677.618	135			
2	Regression	1003.320	7	143.331	27.208	.000 <sup>b</sup>
	Residual	674.298	128	5.268		
	Total	1677.618	135			

- a. Predictors: (Constant), participant gender
- b. Predictors: (Constant), participant gender, SFHLprose, General Numeracy total score, SFHL numeracy total score, Math anxiety total score, Revised Education Scores, Health Numeracy total score
- c. Dependent Variable: Total Comprehension score general and specific

#### Coefficient's

			dardized cients	Standardized Coefficients			5% Confidenc	e Interval for	Collingarity	Statistics
Model	İ	B	Std. Error	Beta	+	Sig.		Upper Bound	1	VIF
1	(Constant)	17,743	.592	Deta	29.991	.000	16.573	18.913	Tolerance	VII
	participant gender	-1.179	.687	147	-1.717	.088	-2.536	.179	1.000	1.000
2	(Constant)	2.485	1.822		1.364	.175	-1.121	6.091		
	participant gender	.421	.481	.052	.874	.384	531	1.372	.876	1.142
	Revised Education Scores	.363	.231	.108	1.573	.118	094	.820	.671	1.491
	SFHL numeracy tota score	.100	.060	.105	1.686	.094	017	.218	.808	1.237
	Math anxiety total so	010	.027	023	373	.710	062	.043	.810	1.234
	Health Numeracy tot score	.812	.130	.451	6.242	.000	.555	1.070	.601	1.664
	General Numeracy total score	.446	.226	.132	1.971	.051	002	.893	.697	1.435
	SFHLprose	.084	.021	.260	3.895	.000	.041	.126	.707	1.415

a. Dependent Variable: Total Comprehension score general and specific

## Parsimonious Total Risk Comprehension Final Regression Model

## Coefficients(a)

Model		Unstandardize d Coefficients Std.		Standard ized Coefficie nts			95% Confidence Interval for B		Collinearity Statistics	
		В	Error	Beta	t	Sig.	Lower Bound	Upper Bound	Toler ance	VIF
1	(Constant)	5.186	1.850		2.804	.006	1.528	8.845		
	participant gender	.000	.467	.000	.000	1.000	923	.923	.943	1.060
	participant age	678	.236	186	- 2.872	.005	-1.144	211	.769	1.300
	SFHL numeracy total score	.146	.061	.153	2.407	.017	.026	.266	.803	1.246
	Health Numeracy total score	.838	.120	.468	7.000	.000	.601	1.074	.721	1.386
	SFHLprose	.067	.021	.224	3.268	.001	.027	.108	.688	1.454

a Dependent Variable: Total Comprehension score (general and specific scores combined)

# *'Uncommon' Risk Comprehension Regression Model A Priori Explanatory Variables*

## **Descriptive Statistics**

	Mean	Std. Deviation	N
Specific Comprehension total score	7.6544	2.35821	136
participant gender	.74	.439	136
Revised Education Scores	2.4265	1.04444	136
SFHL numeracy total score	26.2500	3.68932	136
Math anxiety total score	23.6544	8.25912	136
Health Numeracy total score	5.9265	1.95744	136
General Numeracy total score	1.3750	1.04660	136
SFHLprose	64.1471	10.95616	136

## **ANOVA<sup>c</sup>**

Model		Sum of Squares	df	Mean Square	F	Cia
Model		Squares	uı	Mean Square	Г	Sig.
1	Regression	12.598	1	12.598	2.287	.133 <sup>a</sup>
	Residual	738.160	134	5.509		
	Total	750.757	135			
2	Regression	421.851	7	60.264	23.453	.000 <sup>b</sup>
	Residual	328.906	128	2.570		
	Total	750.757	135			

- a. Predictors: (Constant), participant gender
- b. Predictors: (Constant), participant gender, SFHLprose, General Numeracy total score, SFHL numeracy total score, Math anxiety total score, Revised Education Scores, Health Numeracy total score
- C. Dependent Variable: Specific Comprehension total score

#### Coefficients

			dardized icients	Standardized Coefficients			% Confidence	e Interval fo	collinearity	/ Statistics
Mode	el	В	Std. Error	Beta	t	Sig.	ower Bound	Jpper Bound	Tolerance	VIF
1	(Constant)	8.171	.397		20.597	.000	7.387	8.956		
	participant gender	696	.460	130	-1.512	.133	-1.607	.214	1.000	1.000
2	(Constant)	-1.580	1.273		-1.242	.217	-4.098	.938		
	participant gender	.302	.336	.056	.899	.370	363	.967	.876	1.142
	Revised Education Scores	.211	.161	.093	1.309	.193	108	.530	.671	1.491
	SFHL numeracy to score	.043	.042	.068	1.041	.300	039	.126	.808	1.237
	Math anxiety total	006	.019	021	329	.743	043	.031	.810	1.234
	Health Numeracy score	.380	.091	.315	4.178	.000	.200	.560	.601	1.664
	General Numerac total score	.570	.158	.253	3.607	.000	.257	.882	.697	1.435
	SFHLprose	.070	.015	.324	4.654	.000	.040	.099	.707	1.415

a. Dependent Variable: Specific Comprehension total score

## Parsimonious 'Uncommon' Risk Comprehension Regression Model

## Coefficients(a)

Mod	lel	Unstand Coefficie	dardized ents Std. Error	Standardi zed Coefficien ts	t	Sig.	95% Confi Interval for Lower Bound		Collinea Statistic Tolera nce	,
1	(Constant)	8.189	.382		21.43 7	.000	7.434	8.945		
	gender	743	.445	141	-1.667	.098	-1.623	.138	1.000	1.000
2	(Constant)	.128	.847		.151	.880	-1.547	1.803		
	participant gender Health	016	.330	003	047	.962	668	.637	.937	1.068
	Numeracy total score	.386	.088	.326	4.411	.000	.213	.560	.668	1.497
	SFHLprose	.070	.013	.353	5.367	.000	.044	.096	.847	1.181
	General Numeracy total score	.586	.154	.262	3.801	.000	.281	.890	.770	1.298

a Dependent Variable: Specific Comprehension total score

# *'Common' Risk Comprehension* Regression Model *A Priori* Explanatory Variables

## **Descriptive Statistics**

	Mean	Std. Deviation	N
General Comprehension total score	9.21	1.697	136
participant gender	.74	.439	136
Revised Education Scores	2.4265	1.04444	136
SFHL numeracy total score	26.2500	3.68932	136
Math anxiety total score	23.6544	8.25912	136
Health Numeracy total score	5.9265	1.95744	136
General Numeracy total score	1.3750	1.04660	136
SFHLprose	64.1471	10.95616	136

## **ANOVA<sup>c</sup>**

		Sum of	16		1	0;
Model		Squares	df	Mean Square	F	Sig.
1	Regression	6.047	1	6.047	2.117	.148 <sup>a</sup>
	Residual	382.769	134	2.856		
	Total	388.816	135			
2	Regression	146.706	7	20.958	11.080	.000 <sup>b</sup>
	Residual	242.110	128	1.891		
	Total	388.816	135			

- a. Predictors: (Constant), participant gender
- b. Predictors: (Constant), participant gender, SFHLprose, General Numeracy total score, SFHL numeracy total score, Math anxiety total score, Revised Education Scores, Health Numeracy total score
- c. Dependent Variable: General Comprehension total score

## Coefficients

			dardized icients	Standardized Coefficients			6 Confidence	ce Interval fo	ollinearity	Statistic:
Mode	el	В	Std. Erroi	Beta	t	Sig.	ower Bound	Jpper Bound	Folerance	VIF
1	(Constant)	9.571	.286		33.504	.000	9.006	10.136		
	participant gende	482	.332	125	-1.455	.148	-1.138	.173	1.000	1.000
2	(Constant)	4.065	1.092		3.723	.000	1.905	6.226		
	participant gende	.118	.288	.031	.411	.682	452	.689	.876	1.142
	Revised Educatio Scores	.152	.138	.094	1.099	.274	122	.426	.671	1.491
	SFHL numeracy t score	.057	.036	.124	1.601	.112	013	.128	.808	1.237
	Math anxiety total	004	.016	018	238	.812	035	.028	.810	1.234
	Health Numeracy score	.433	.078	.499	5.547	.000	.278	.587	.601	1.664
	General Numerac total score	124	.135	076	915	.362	392	.144	.697	1.435
	SFHLprose	.014	.013	.089	1.077	.284	012	.039	.707	1.415

a. Dependent Variable: General Comprehension total score

## Parsimonious 'Common' Risk Comprehension Regression Model

#### Coefficient®

		Unstandardized Coefficients		Standardized Coefficients			5% Confidenc	e Interval for E	Collinea Statist	, ,
Model		В	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound	Tolerance	VIF
1	(Constant)	9.432	.287		32.852	.000	8.865	10.000		
	participant gende	394	.335	100	-1.176	.242	-1.055	.268	1.000	1.000
2	(Constant)	4.970	.962		5.167	.000	3.068	6.873		
	participant gende	.118	.281	.030	.419	.676	438	.673	.947	1.055
	Health Numeracy total score	.401	.070	.453	5.693	.000	.262	.541	.756	1.323
	SFHL numeracy total score	.087	.035	.184	2.465	.015	.017	.157	.856	1.168
	participant age	264	.131	146	-2.022	.045	523	006	.912	1.097

a. Dependent Variable: General Comprehension total score

#### References

- Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, A.M.A. (1999). Health Literacy: Report of the Council on Scientific Affairs. *JAMA*, 281, 552-557.
- Adelsward, V., & Sachs, L. (1996). The meaning of 6.8: Numeracy and normality in health information talks. *Social Science & Medicine*, 43, 1179-1187.
- Agre, P., Stieglitz, E., & Milstein, G. (2006). The case for development of a new test of health literacy. *Oncology Nursing Forum*, *33*, 283-289.
- Ahlers-Schmidt, C.R., Golbeck, A.L., Paschal, A.M., Zackula, R., and Taylor, N.T. (2006). Breast cancer counts: numeracy in breast cancer information on the web. *Journal of Cancer Education*, 21, 95-98.
- Ashcraft, M.H. (2002). Math anxiety: personal, educational, and cognitive consequences. *Current Directions in Psychological Science*, 11, 181-185.
- Ashcraft, M. H., & Faust, M. W. (1994). Mathematics anxiety and mental arithmetic performance: an exploratory investigation. *Cognition and Emotion*, 8, 97-125.
- Ashcraft, M. H., & Kirk, E. P. (2001). The relationship between working memory, math anxiety, and performance. *Journal of Experimental Psychology: Learning, Memory, and Cognition*, 27, 157-175.
- Baker, D. W., Gazmararian, J. A., Sudano, J., & Patterson, M. (2000). The association between age and health literacy among elderly persons. *The Journals of Gerontology Series B*, 55, S368-S374.
- Baker, D. W., Gazmararian, J. A., Williams, M. V., Scott, T., Parker, R. M., Green, D., et al. (2002). Functional Health Literacy and the Risk of Hospital Admission Among Medicare Managed Care Enrollees. *American Journal of Public Health*, 92, 1278-1283.
- Baker, D. W., Gazmararian, J. A., Williams, M. V., Scott, T., Parker, R. M., Green, D., et al. (2004). Health Literacy and Use of Outpatient Physician Services by Medicare Managed Care Enrollees. *J Gen Intern Med*, 19, 215-220.
- Baker, D. W., Parker, R. M., Williams, M. V., & Clark, W. S. (1998). Health Literacy and the Risk of Hospital Admission. *J Gen Intern Med*, *13*, 791-798.
- Baker, D. W., Parker, R. M., Williams, M. V., Clark, W. S., & Nurss, J. (1997). The relationship of patient reading ability to self-reported health and use of health services. *American Journal of Public Health*, 87, 1027-1030.
- Baker, D. W., Williams, M. V., Parker, R. M., Gazmararian, J. A., & Nurss, J. (1999). Development of a brief test to measure functional health literacy. *Patient education and counseling*, *38*, 33-42.

- Baron, R. M., & Kenny, D. A. (1986). The Moderator-Mediator Variable Distinction in Social Psychological Research: Conceptual, Strategic, and Statistical Considerations. *Journal of Personality and Social Psychology*, *51*, 1173-1182.
- Beier, M. E., & Ackerman, P. L. (2005). Age, ability, and the role of prior knowledge on the acquisition of new domain knowledge: promising results in a real-world learning environment. *Psychology and Aging*, 20, 341-355.
- Benson, J. G., & Forman, W. B. (2002). Comprehension of written healthcare information in an affluent geriatric retirement community: use of the Test of Functional Health Literacy. *Gerontology*, 48, 93-97.
- Berry, L. L., Seiders, K., & Wilder, S. S. (2003). Innovations in access to care: a patient centered approach. *Annals of Internal Medicine*, *139*, 568-574.
- Bogardus, S. T., Jr, Holmboe, E., & Jekel, J. F. (1999). Perils, Pitfalls, and Possibilities in Talking About Medical Risk. *JAMA*, 281, 1037-1041.
- Bottorff, J. L., Ratner, P. A., Johnson, J. L., Lovato, C. Y., & Joab, S. A. (1996). *Uncertainties and Challenges. Communicating Risk in the Context of Familial Cancer*: The National Cancer Insitute of Canada.
- Boyd, J. H., Watkins, A. R., Price, C. L., Fleming, F., & DeBaun, M. R. (2005). Inadequate community knowledge about sickle cell disease among African-American women. *Journal of the National Medical Association*, 97, 62-67.
- Brewer, M.B. (2000). Research Design and Issues of Validity. In Handbook of Research Methods in Social and Personality Psychology. Ed. Ries, H.T. & Judd, C.M., Cambridge University Press, New York, NY, USA.
- Bunker, J. P., Houghton, J., & Baum, M. (1998). Putting the risk of breast cancer in perspective. *BMJ*, *317*, 1307-1309.
- Burkell, J. (2004). What are the chances? Evaluating risk and benefit information in consumer health materials. *J Med Libr Assoc.*, 92, 200-208.
- Canadian Cancer Society. (2006). *Canadian Cancer Society Statistics*: Canadian Cancer Society, available at: <a href="http://www.cancer.ca">http://www.cancer.ca</a>.
- Cassell, E. J., Leon, A. C., & Daufman, S. G. (2001). Preliminary evidence of impaired thinking in sick patients. *Annals of Internal Medicine*, *134*,1120-1123.
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared Decision-Making in the Medical Encounter: What Does It Mean? (Or It Takes Least Two To Tango). *Social Science & Medicine*, 44, 681-692.
- Charles, C., Whelan, T., & Gafni, A. (1999). What do we mean by partnership in making decisions about treatment? *BMJ*, 319, 780-782.

- Center for Healthcare Strategies Inc. (CHCS) (2000). Fact sheet: What is health literacy? Princeton, NJ., available at: <a href="http://www.chcs.org/usr\_doc/Health\_Literacy\_Fact\_Sheets.pdf">http://www.chcs.org/usr\_doc/Health\_Literacy\_Fact\_Sheets.pdf</a>
- Centre for Literacy. (2006). *Definition of Literacy*. Accessed June 2006, available at: http://www.centreforliteracy.qc.ca/def.htm
- Centre for Literacy Quebec (2001). Background document on literacy and health, available at: <a href="http://www.nald.ca/PROVINCE/QUE/litent/health/finalsum/bd/bd3-sec1.html">http://www.nald.ca/PROVINCE/QUE/litent/health/finalsum/bd/bd3-sec1.html</a>.
- Choi, J., & Hannafin, M. (1997). The effects of instructional context and reasoning compexity on mathematics problem-solving. *Educational Technology Research and Development*, 45, 43-55.
- Cline, R.J.W. & Haynes, K.M., (2001). Consumer health information seeking on the Internet: the state of the art. *Health Education Research*, 16, 671-692.
- Cloer, T. (1981). Factors affecting comprehension of math word problems. A review of the literature: ERIC Docment Reproduction Service. No. ED209655.
- Curcio, F. R. (1987). Comprehension of mathematical relationships expressed in graphs. *Journal for Research in Mathematics Education*, *18*, 382-393.
- Davids, S. L., Schapira, M. M., McAuliffe, T. L., & Nattinger, A. B. (2004). Predictors of pessimistic breast cancer risk perceptions in a primary care population. *J Gen Intern Med*, *19*, 310-315.
- Davis, T. C., Michielutte, R., Askov, E. N., Williams, M. V., & Weiss, B. D. (1998). Practical Assessment of Adult Literacy in Healthcare. *Health Education & Behavior*, 25, 613-624.
- Davis, T. C., Williams, M. V., Marin, E., Parker, R. M., & Glass, J. (2002). Health Literacy and Cancer Communication. *CA Cancer J Clin*, 52, 134-149.
- Davis, T. C., & Wolf, M. S. (2004). Health literacy: implications for family medicine. *Family Medicine*, *36*, 595-598.
- Detsky, A. S., & Redelmeier, D. A. (1998). Measuring Health Outcomes Putting Gains into Perspective. *N Engl J Med*, *339*, 402-404.
- Dingwall, J. (2000). *Improving Numeracy in Canada*: National Literacy Secretariat, available at: <a href="https://www.nald.ca/nls/inpub/numeracy/improve/contents.htmw">www.nald.ca/nls/inpub/numeracy/improve/contents.htmw</a>.
- Donelle, L., Arocha, J. F., & Hoffman-Goetz, L. (in press). *Assessing Health Numeracy Among Community Dwelling Older Adults*. Journal of Health Communication.
- Eiser, J. (1998). Communication and interpretation of risk. *Br Med Bull*, 54, 779-790.

- Epstein, R. M., Alper, B. S., & Quill, T. E. (2004). Communicating Evidence for Participatory Decision Making. *JAMA*, 291, 2359-2366.
- Estey, A., Musseau, A., & Keehn, L. (1991). Comprehension levels of patients reading health information. *Patient Education and Counseling*, *18*, 165-169.
- Estrada, C., Martin-Hryniewics, M., Peek, B., Collins, C., & Byrd, J. (2004). Literacy and numeracy skills and anticoagulation control. *American Journal of the Medical Sciences*, 328, 88-93.
- Estrada, C., Martin-Hryniewicz, M., Barnes-Higgs, V., Collins, C., & Byrd, J. C. (2000). Anticoagulant Patient Information Material is Written at High Readability Levels. *Stroke*, *31*, 2966.
- Eysenbach, G. (1999). Towards the millennium of cybermedicine. *J Med Internet Res*, 1 (suppl 1), e2.
- Eysenbach, G. (2003). The impact of the Internet on cancer outcomes. *CA Cancer J Clin*, 53, 365-371.
- Faust, M. W., Ashcraft, M. H., & Fleck, D. E. (1996). Mathematics anxiety effects in simple and complex addition. *Mathematical Cognition*, 2, 25-62.
- Flanagan, D. P., McGrew, K. S., Abramowitz, E., Lehner, L., Untiedt, S., Berger, D., et al. (1997). Improvement in Academic Screening Instruments? A Concurrent Validity Investigation of the K-FAST, MBA, and WRAT-3. *Journal of Psychoeducational Assessment*, 15, 99-112.
- Fox, S., & Rainie, L. (2000). *The online healthcare revolution: how the web helps*Americans take better care of themselves. Washington, DC: The Pew Internet and American Life Project.
- Friedman, D. B., & Hoffman-Goetz, L. (in press). An exploratory study of older adults' comprehension of printed cancer information: Is readability a key factor? *Journal of Health Communication*.
- Friedman, D. B., & Hoffman-Goetz, L. (2003). Cancer coverage in North American publications targeting seniors. *Journal of Cancer Education*, 18, 215-222.
- Friedman, D. B., Hoffman-Goetz, L., & Arocha, J. F. (2004). Readability of cancer information on the Internet. *Journal of Cancer Education*, 19, 117-122.
- Friedman, D. B., Hoffman-Goetz, L., & Arocha, J. F. (2006). Health literacy and the world wide web: comparing the readability of leading incident cancers on the Internet. *Medical Informatics & the Internet in Medicine*, *31*, 67-87.
- Fuller, R., Dudley, N., & Blacktop, J. (2001). Risk communication and older people-understanding of probability and risk information by medical inpatients aged 75 years and older. *Age and Ageing*, *30*, 473-476.

- Gal, I. (1993). *Issues and challenges in adult numeracy* (No. TR93-15): National Center on Adult Literacy.
- Garbers, S., & Chiasson, M. A. (2004). Inadequate functional health literacy in Spanish as a barrier to cervical cancer screening among immigratn latinas in New York City. *Preventing Chronic Disease Public Health Research, Practice and Policy,* 1, A07.
- Gazmararian, J. A., Baker, D. W., Williams, M. V., Parker, R. M., Scott, T. L., Green, D. C., et al. (1999). Health Literacy Among Medicare Enrollees in a Managed Care Organization. *JAMA*, *281*, 545-551.
- Gazmararian, J. A., Williams, M. V., Peel, J., & Baker, D. W. (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling*, *51*, 267-275.
- Golbeck, A. L., Ahlers-Schmidt, C. R., & Paschal, A. M. (2005a). Health literacy and adult basic education assessments. *Adult Basic Education*, *15*, 151-168.
- Golbeck, A. L., Ahlers-Schmidt, C. R., Paschal, A. M., & Dismuke, S. E. (2005b). A Definition and Operational Framework for Health Numeracy. *American Journal of Preventive Medicine*, 29, 375-376.
- Guerra, C. E., Dominguez, F., & Shea, J. A. (2005). Literacy and knowledge, attitudes, and behavior about colorectal cancer screening. *Journal of Health Communication*, *10*, 651-663.
- Gurmankin, A. D., Baron, J., & Armstrong, K. (2004). The effect of numerical statements of risk on trust and comfort with hypothetical physician risk communication. *Med Decision Making*, 24, 265-271.
- Hanoch, Y.& Pachur, T. (2004). Nurses as information providers: facilitating understanding and communication of statistical information. *Nurs Educ Today*, 24, 236-243.
- Hay, J., Shuk, E., Cruz, G., & Ostroff, J. (2005). Thinking through cancer risk: characterizing smokers' process of risk determination. *Qualitative Health Research*, 15, 1074-1085.
- Health Canada. (2003). *How Does Literacy Affect the Health of Canadians?* : Health Canada, available at: <a href="http://www.phac-aspc.gc.ca/ph-sp/phdd/literacy/literacy.html">http://www.phac-aspc.gc.ca/ph-sp/phdd/literacy/literacy.html</a>.
- Hirsch, E. D. (2003). Reading comprehension requires knowledge of the words and the world: available at:

  <u>www.coreknowledge.org/CKpronto2/about/CommonKnowledge/V16iiJune200</u>
  3/AE\_SPRNG.pdf.
- Hopko, D. R. (2003). Confirmatory Factor Analysis Of The Math Anxiety Rating Scale-Revised. *Educational and Psychological Measurement*, *63*, 336-351.

- Hopko, D. R., Mahadevan, R., Bare, R. L., & Hunt, M. K. (2003a). The Abbreviated Math Anxiety Scale (AMAS) Construction, Validity, and Reliability. *Assessment*, 10, 178-182.
- Hopko, D. R., McNeil, D. W., Lejuez, C. W., Ashcraft, M. H., Eifert, G. H., & Riel, J. (2003b). The effects of anxious responding on mental arithmetic and lexical decision task performance. *Journal of Anxiety Disorders*, 17, 647-665.
- Hopwood, P. (2000). Breast cancer risk perception: what do we know and understand? *Breast Cancer Res.*, 2, 287-391.
- HRSDC. (2004). *Reading the Future: A Portrait of Literacy in Canada Highlights*: National Literacy Secretariate, available at: <a href="http://www.hrsdc.gc.ca/en/hip/lld/nls/Surveys/ialscrh.shtml#top">http://www.hrsdc.gc.ca/en/hip/lld/nls/Surveys/ialscrh.shtml#top</a>.
- IOM. (2001). *Crossing the Quality Chasm. A New Health System for the 21st Century*. Retrieved June 30, 2006, from <a href="http://www.nap.edu/">http://www.nap.edu/</a>
- IOM. (2004). *Health Literacy: A Prescription to End Confusion*: The National Academies Press.
- Jones, C. J. (2001). CBA's that work. Assessing student's math content-reading levels. *Teaching Exceptional Children*, *34*, 24-28.
- Julian-Reynier, C., Welkenhuysen, M., Hagoel, L., Decruyenarere, M., & Hopwood, P. (2003). Risk communication strategies: state of the art and effectiveness in the context of cancer genetic services. *European Journal of Human Genetics*, 11, 725-736.
- Kalichman, S. C., Benotsch, E., Suarez, T., Catz, S., & Miller, J. (2000). Health literacy and health-related knowledge among persons living with HIV/AIDS. *American Journal of Preventive Medicine*, *18*, 325-331.
- Kalichman, S. C., Ramachandran, B., & Catz, S. (1999). Adherence to Combination Antiretroviral Therapies in HIV Patients of Low Health Literacy. *J Gen Intern Med*, 14, 267-273.
- Kickbusch, I. S. (2001). Health literacy: addressing the health and education divide. *Health Promot. Int.*, *16*, 289-297.
- Klimczak, N. C., Bradford, K. A., Burright, R. G., & Donovick, P. J. (2000). K-FAST and WRAT-3: Are They Really Different? *The Clinical Neuropsychologist*, 14, 135-138.
- Konold, C., Pollatsek, A., Well, A., Lohmeier, J., & Lipson, A. (1993). Inconsistencies in students' reasoning about probability. *Journal of Research in Mathematics Education*, 24, 392-414.
- Koo, M., Krass, I., & Aslani, P. (2006). Enhancing patient education about medicines: factors influencing reading and seeking of written medicine information. *Health Expectations*, *9*, 174-187.

- Kreuter, M. W. (1999). Dealing With Competing and Conflicting Risks in Cancer Communication. *J Natl Cancer Inst Monographs*, 25, 27-35.
- Lanine, A. D., Jayaratne, T. E., Sheldon, J. P., Kardia, S. L. R., Anderson, E. S., Feldbaum, M., et al. (2004). Exploring the public understanding of basic genetic concepts. *Journal of Genetic Counseling*, *13*, 305-320.
- Lipkus, I. M., Samsa, G., & Rimer, B. K. (2001). General performance on a numeracy scale among highly educated samples. *Medical decision making: an international journal of the Society for Medical Decision Making*, 21, 37-44.
- Littenberg, B. (1994). When Numbers get Serious. J Gen Intern Med, 7, 295-296.
- Lynch, W. J. (1995). Achievement testing in traumatic brain injury: Two new approaches. *J Head Trauma Rehabil*, *10*, 95-98.
- Manusco, C. A., & Rincon, M. (2006). Asthma patients' assessment of healthcare and medical decision making: the role of health literacy. *Journal of Asthma*, 43, 41-44.
- Mazur, D. J., Hickman, D. H. (1991). Patient's Interpretations of Probability Terms. *J Gen Intern Med*, 6, 237-240.
- McLaughlin, G. H. (1969). SMOG grading a new readability formula. *Journal of Reading*, 12, 639-649.
- Meade, C.D. & Smith, C.F. (1991). Readability formulas: cautions and criteria. *Patient Education and Counseling*, 17, 153-158.
- Mika, V. S., Kelly, P. J., Price, A., Franquiz, M., & Villarreal, R. (2005). The ABC's of health literacy. *Family and Community Health*, 28, 351-357.
- Morris, N. S., MacLean, C. D., Chew, L., & Littenberg, B. (2006). The single item literacy screener: evaluation of a brief instrument to identify limited reading ability. *BioMed Central Family Practice*, 7, 21-28.
- NCES. (2005). *Highlights from the 2003 International Adult Literacy and Lifeskills Survey (ALL)*: U.S. Department of Education.
- NCES. (2006). A first look at the literacy of America's adults in the 21st century: U.S. Department of Education Institute of Education Sciences.
- Nielsen-Bohlman, L., Panzer, A.M., Kindig, D.A. (2004). Health literacy: A prescription to end confusion. Retrieved July 2006, from <a href="http://nap.educ/catalog/10883.html">http://nap.educ/catalog/10883.html</a>
- Nurss, J., Parker, R. M., & Baker, D. W. (1995). TOFHLA: Test of Functional Health Literacy for Adults: Peppercorn Books and Press, Inc.

- Nutbeam, D. (2000). Health literacy as a public health goal: a challenge for contemporary health education and comunication strategies into the 21st century. *Health Promotion International*, 15, 259-267.
- Paasche-Orlow, M. K., Parker, R. M., Gazmararian, J. A., Nielsen-Bohlman, L. T., & Rudd, R. R. (2005). The Prevalence of Limited Health Literacy. *Journal of Internal Medicine*, 20, 175-184.
- Paling, J. (2003). Strategies to help patients understand risks. BMJ, 327, 745-748.
- Parker, R. M., Baker, D. W., Williams, M. V., & Nurss, J. R. (1995). The Test of Functional Health Literacy in Adults: A New Instrument for Measuring Patients' Literacy Skills. *J Gen Intern Med*, *10*, 537-541.
- Paulos, J. A. (1989). *Innumeracy: Mathematical Illteracy and Its Consquences* (6th ed.). Toronto: Collins Publishers.
- Peters, E., McCaul, K. D., Stefanek, M., & Nelson, W. (2006a). A heuristics approach to understanding cancer risk perception: contributions from judgment and decision-making research. *Ann Behav Med*, *31*, 45-52.
- Peters, E., Vastfjall, D., Slovic, P., Mertz, C. K., Mazzocco, K., & Dickert, S. (2006b). Numeracy and decision making. *Psychological Science*, *17*, 407-413.
- Powell, C. K., & Kripalani, S. (2005). Brief report: resident recognition of low literacy as a risk factor in hospital readmission. *J Gen Intern Med*, 20, 1042-1044.
- Reid, J. C., Kardash, C. M., & Robinson, R. D. (1994). Comprehension in patient literature: the importance of text and reader characteristics. *Health Communication*, *6*, 327-335.
- Richards, M. (1996). Lay and professional knowledge of genetics and inheritance. *Public Understanding of Science*, *5*, 217-230.
- Riche, J. M., Reid, J. C., Robinson, R. D., & Kardash, C. M. (1991). Text and reader characteristics affecting the readability of patient literature. *Reading Improvement*, 28, 287-292.
- Rimer, B. K., & Glassman, B. (1999). Is There a Use for Tailored Print Communications in Cancer Risk Communication? *J Natl Cancer Inst Monographs*, 1999, 140-148.
- Rothman, A. J., & Kiviniemi, M. T. (1999). Treating people with information: an analysis and review of approaches to communicating health risk information. *Journal of the National Cancer Institute Monographs*, 25, 44-51.
- Samuelstuen, M. S., & Braten, I. (2005). Decoding, knowledge, and strategies in comprehension of expository text. *Scandinavian Journal of Psychology*, 46, 107-117.

- Schapira, M. M., Davids, S. L., McAuliffe, T. L., & Nattinger, A. B. (2004). Agreement between scales in the measurement of breast cancer risk perceptions. *Risk Analysis*, 24, 665-673.
- Schapira, M. M., Nattinger, A. B., & McHorney, C. A. (2001). Frequency or probability? A qualitative study of risk communication formats used in healthcare. *Medical Decision Making*, *21*, 459-467.
- Schillinger, D., Barton, L. R., Karter, A. J., Wang, F., & Adler, N. (2006). Does literacy mediate the relationship between education and health outcomes? A study of a low-income population with diabetes. *Public Health Reports*, 121, 245-254.
- Schillinger, D., Bindman, A., Wang, F., Stewart, A., & Piette, J. (2004). Functional health literacy and the quality of physician-patient communication among diabetes patients. *Patient Education and Counseling*, *52*, 315-323.
- Schillinger, D., Grumbach, K., Piette, J., Wang, F., Osmond, D., Daher, C., et al. (2002). Association of Health Literacy With Diabetes Outcomes. *JAMA*, 288, 475-482.
- Schmitter-Edgecombe, M., & Simpson, A. L. (2001). Effects of age and intentionality on content memory and temporal memory for performed activities. *Aging, Neuropsychology, and Cognition, 8*, 81-97.
- Schwartz, L., Woloshin, S., Black, W., & Welch, H. (1997). The role of numeracy in understanding the benefit of screening mammography. *Ann Intern Med*, *127*, 966-972.
- Schwartz, L. M., Woloshin, S., & Welch, H. G. (2005). Can patients interpret health information? An assessment of the medical data interpretation test. *Med Decision Making*, *25*, 290-300.
- Schwartz, S. R., McDowell, J., & Yueh, B. (2004). Numeracy and the shortcomings of utility assessment in head and neck cancer patients. *Head Neck*, 26, 401-407.
- National Cancer Institute (NCI) (2001). *Making health communication programs work*, available at: <a href="http://www.cancer.gov/pinkbook">http://www.cancer.gov/pinkbook</a>
- Sheridan, S., Pignone, M., & Lewis, C. (2003). A Randomized Comparison of Patients' Understanding of Number Needed to Treat and Other Common Risk Reduction Formats. *J Gen Intern Med*, *18*, 884-892.
- Sheridan, S. L. & Pignone, M. (2002). Numeracy and the medical student's ability to interpret data. *Effective clinical practice: ECP*, *5*, 35-40.
- Silver, E. A. (1981). Recall of mathematical problem information: solving related problems. *Journal for Research in Mathematics Education*, *12*, 54-64.
- Sliwinski, M. (1997). Aging and Counting Speed: Evidence for Process-Specific Slowing. *Psychology and Aging*, *12*, 38-49.

- Speros, C. (2005). Health literacy: Concept analysis. *Journal of Advanced Nursing*, 50, 633-640.
- Spires, H. A., & Donley, J. (1998). Prior knowledge activation: inducing engagement with informal texts. *Journal of Educational Psychology*, 90, 249-260.
- Statistics Canada. (2000). *HRDC International Adult Literacy Survey. Literacy in the Information Age. Final Report of the IALS*.: Statistics Canada, available at: http://www1.oecd.org/publications/e-book/8100051e.pdf.
- Statistics Canada. (2004). *Households using the Internet from home, by purpose of use*: Government of Canada, available at: <a href="http://www40.statcan.ca/101/cst01/arts52a.htm">http://www40.statcan.ca/101/cst01/arts52a.htm</a>.
- Statistics Canada. (2005a). Building on our Competencies: Canadian Results of the International Adult Literacy and Skills Survey Catalogue no. 89-617-XIE. Ottawa: Human Resources and Skills Development Canada, available at: www.statcan.ca.
- Statistics Canada. (2005b). *Characteristics of household Internet users*: Government of Canada, available at: www.40.statcan.ca/101/cst01/comm10a.htm.
- Statistics Canada. (2005c). Learning a living: the first results of the adult literacy and life skills survey. Ottawa and Paris: Organization for Economic Co-operation and Development.
- Steen, L. (1990). Numeracy. Daedalus, 119, 211-231.
- Steen, L. (1999). Numeracy: The new Literacy for a Data-Drenched Society. *Educational Leadership*, *57*, 8-13.
- Steen, L. (2001a). Mathematics and numeracy: two literacies, one language. *The Mathematic Educator*, 6, 10-16.
- Steen, L. (Ed.). (2001b). *Mathematics and democracy: The case for quantitative literacy*: The National Council on Education and the Disciplines.
- Sutherland, H. J., Lockwood, G. A., Tritchler, D. L., Sem, F., Brooks, L., & Till, J. E. (1991). Communicating Probabilitatic Information to Cancer Patients: Is There 'Noise' on the Line? *Social Science & Medicine*, *32*, 725-731.
- Walter, L. C., & Covinsky, K. E. (2001). Cancer Screening in Elderly Patients: A Framework for Individualized Decision Making. *JAMA*, 285, 2750-2756.
- Wegener, D.T. & Fabrigar, L.R. (2000). Analysis and design for non-experimental data. Addressing causal and noncausal hypotheses. In: *Handbook of Research Methods in Social and Personality Psychology*. Ed: Ries, H.T. & Judd, C.M., Cambridge University Press, New York, N.Y., USA.
- Weinfurt, K. P., DePuy, V., Castel, L. D., Sulmasy, D. P., Schulman, K. A., & Meropol, M. J. (2004). Understanding of an aggregate probability statement by patients

- who are offered participation in phase 1 clinical trials. *Cancer Causes and Control*, 103, 140-147.
- Weinstein, N. D. (1999). What Does It Mean to Understand a Risk? Evaluating Risk Comprehension. *J Natl Cancer Inst Monographs*, 25, 15-20.
- Weinstein, N. D., Atwood, K. A., Puleo, E., Fletcher, R., Colditz, G. A., & Emmons, K. (2004). Colon Cancer: Risk Perceptions and Risk Communication. *Journal of Health Communication*, *9*, 53-65.
- Weiss, B. D., Mays, M. Z., Martz, W., Castro, K. M., DeWalt, D. A., Pignone, M. P., et al. (2005). Quick assessment of literacy in primary care: the newest vital sign. *Annals of Family Medicine*, *3*, 514-522.
- Wideroff, L., Vadaparampil, S. T. V., Greene, M. H., Taplin, S., Olson, L., & Freedman, A. N. (2005). Hereditary breast/ovarian and colorectal cancer genetics knowledge in a national sample of US physicians. *Journal of Medical Genetics*, 42, 749-755.
- Williams, M. V., Parker, R. M., Baker, D. W., Parikh, N. S., Pitkin, K., Coates, W. C., et al. (1995). Inadequate functional health literacy among patients at two public hospitals. *JAMA*, *274*, 1677-1682.
- Wolf, M. S., Gazmararian, J. A., & Baker, D. W. (2006). Health literacy and functional health status among older adults. *Arch Intern Med*, *165*, 1946-1952.
- Woloshin, S., Schwartz, L.M. & Welch, H. G. (2005). Patients and Medical Statistics. Interest, Confidence, and Ability. *J Gen Intern Med*, 20, 996-1000.
- Woloshin, S., Schwartz, L. M., Black, W. C., & Welch, H. G. (1999). Women's perceptions of breast cancer risk: how you ask matters. *Med Decision Making*, 19, 221-229.
- Woloshin, S., Schwartz, L. M., Moncur, M., Gabriel, S., & Tosteson, A. N. (2001). Assessing values for health: numeracy matters. *Medical Decision Making: an International Journal of the Society for Medical Decision Making, 21,* 382-390.
- Yagoubi, R. E., Lemaire, P., & Besson, M. (2005). Effects of aging on arithmetic problem-solving: An event-related brain potential study. *Journal of Cognitive Neuroscience*, 17, 37-50.
- Zarcadoolas, C., Pleasant, A., & Greer, D. S. (2005). Understanding health literacy: an expanded model. *Health Promot. Int.*, 20, 195-203.