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FACULTY OF GRADUATE AND
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Ph.D. (Education)

GRADE / DEGREE

Faculty of Education

FACULTÉ, ÉCOLE, DÉPARTEMENT / FACULTY, SCHOOL, DEPARTMENT

The Meaning of Patient Education Experiences for Adults with Limited Literacy and Chronic
Illnesses

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**The Meaning of Patient Education Experiences for
Adults with Limited Literacy and Chronic Illnesses**

Judy King

**Thesis submitted to the
Faculty of Graduate and Postdoctoral Studies
In partial fulfillment of the requirements
For the PhD degree in Education**

**Faculty of Education
University of Ottawa**

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395 Wellington Street
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Your file Votre référence

ISBN: 978-0-494-32406-6

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ISBN: 978-0-494-32406-6

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Acknowledgements

Firstly, I have to thank the participants. Without their willingness to allow me into their lives I would not have been able to complete my PhD. I hope I do them proud. As well, I would not have been able to carry out this research if it had not been for the literacy coordinators and instructors who went beyond the call of duty to help me. Their commitment to their students was awe-inspiring.

I would especially like to thank Dr. Maurice Taylor, my advisor, who guided me and got me through the various stages of this long journey. Also thank you to my committee, Dr. Richard Darville, Dr. Paulette Guitard, Dr. Cynthia Morawski, as well as Dr. Allan Quigley, Dr. Jo Logan and Dr. Pierre Boudreau, who all contributed to making my thesis stronger.

A huge thank you to other people involved in literacy and health that have generously helped me. This includes Tannis Atkinson, Lynn Chiarelli, Wendy DesBrisay, Deborah Gordon El-Bihbety, Doris Gillis, Shelley Hourston, Dr. Winston Lawrence, Trudy Lothian, Gord Miller, Fiona Murray, Helen Osborne, Christine Pinsent-Johnson, Darryl Quantz, Audrey Riffenburg, Dr. Irv Rootman, Dr. Rima Rudd, Dr. Maricel Santos, Dr. Linda Shoheit, Dr. Gail Weinstein and the CPHA's National Literacy and Health Partnership.

I would like to thank both Dr. Joan McComas and Dr. Dawn Burnett for their encouragement to begin this PhD and their support along the way that I would actually finish it. Thank you also to the professional colleagues and friends at the Alliance, the Canadian Patient Safety Institute, the Canadian Physiotherapy Association, the Ontario Physiotherapy Association, the Ontario Respiratory Care Society and the Ottawa Hospital.

Thank you to my great magnificence colleagues and friends at Dalhousie University, including Dr. Katherine Harman, Carolyn King, Dr. Lydia Makrides, Nancy Walker and Gail Wainwright, at McGill University including Judy Soicher, and the University of Ottawa

including Jean-Pascal Beaudoin, Dr. Lucie Bousseau, Lynn Casimiro, Dr. Claire-Jehanne Dubouloz, Dr. Andrée Durieux-Smith, Dr. Carol Leonard, Dr. Rose Martini, Dr. Heidi Sveistrup, and Dr. Rachel Thibeau as well as all the cardiorespiratory professors in Canada. Thanks to all the students that have made me a better teacher, physiotherapist and person.

An enormous thank you to the incredible extensive support system of friends that I am blessed to have in my life. Thanks to my inspiring classmates; Ali Abasi, Nahal Akbari, Catherine Elliot, Dr. Nectaria Karagiozis, Dr. Judy Rashotte, Darene Toal-Sullivan, Donna Sharkey, Claire Smith, Sydney Smee, and Mika Yoshimoto. A very special thanks to dear friends Dr. Avril Aitken, Cathy Anderson, Heather Ballarin, Michelle Berg, Kathy Bouchard, Ruth Barclay-Goddard, Madelaine Cherry, Janet Creery, Wilma Jelley, Alain Mayhew, Ellen Melis, Monique Ménard, Audrey Mohr, Marika Morris, Maureen O'Connell, Nathalie Otten, Mal Raddalgoda, Dorianne Sauvé, Ruth Secunda, Diana Sinnige, Steve and Marianne Thornton and Franca Verhoeve and the members of the cone of silence and coffee and cake.

There is literally no way I would have finished this PhD without the never ending support and encouragement of Dr. Gina Bottamini and Dr. Mary Egan who were there every step of the way. And to my best friend Peggy Towler, words can't express my gratitude for having you in my life.

And of course, thanks to my one in a million family, my fantastic father, Les King, my best friend and mother, Josephine King and my wonderful sister, Janice King, and my extended family, who have loved and supported me through out my life. They have always kept me grounded but when I needed them; have given me the wings to fly.

Finally to God, who has blessed me with many gifts and who has always kept me in her loving, protective arms. I will continue to strive to use my many gifts to make this world a better place.

Abstract

There is a direct link between literacy skill level and health. Low literacy skills affect a person's ability to effectively use health services, take medications, and understand other information provided to them regarding their health (Health Canada, 2001). The purpose of this study was to uncover the meaning of patient education experiences for adults living with limited literacy and chronic illnesses. An inductive, interpretive, hermeneutic phenomenological method was used (van Manen, 1997a). A purposeful sample of 14 adults who were attending literacy programs and had chronic illnesses were interviewed. From these interviews, five themes were ascertained: different roles and relationships, living between worlds, language and health care interactions, mismatched expectations, and powerlessness. Adult learning theories helped illuminate how adults with limited literacy and chronic illnesses make meaning of patient education experiences. For the purposes of this study the following adult learning theories were used: Transformational learning theory (Mezirow, 1995), situated cognition theory (Kirshner & Whitson, 1997), and critical theory (Welton, 1995a).

This phenomenological study shone a light on the patient education experiences for adults living with limited literacy and chronic illnesses and exposed the meaning of these experiences as one of a shifting in meaning perspective for the participants. This shifting in meaning perspective was a result of their community of practices within their literacy classrooms which allowed them to enhance their literacy abilities. This, in turn, allowed them to confront the barriers within the health care systems that blocked their full engagement with the health care system. Although some of the barriers continued to exist for the participants, they were better able to identify and confront them.

CHAPTER ONE - INTRODUCTION

In this introductory chapter, the importance of the topic will be presented as well as definitions of key terms. To help situate the research, a presentation of the health care and adult literacy contexts will be offered. Finally, an outline of the organization of the remaining five chapters will conclude this introductory chapter.

Importance of the Topic

There is a direct link between literacy skill level and health. Low literacy skills affect a person's ability to effectively use health services, take medications and understand other information provided to them regarding their health (Health Canada, 2001). Patient education is an essential component of treatment for people with chronic illnesses. During many years of interacting with the health care system, individuals living with chronic illnesses receive much information. This information includes advice regarding exercise, nutrition, medication, and community support services. Information is provided in many forms. Health providers see this advice as vital to maintaining health and quality of life in the face of a chronic condition (Redman, 2004).

The ability of many Canadians to use health information is doubtful when one considers research related to health literacy. The International Adult Literacy Survey (IALS) estimates that 22% of adults in Canada have difficulty in tasks no more complex than determining the maximum number of days they should take a medication by simply looking at the label. An additional 26% of Canadians can only deal with material that is simple, clearly laid out, and put in familiar contexts (Statistics Canada, Human Resources Development Canada, & National Literacy Secretariat, 1996). Furthermore, the preliminary results from the most recent international adult literacy survey conducted in 2003, the Adult Literacy and Life Skills Survey (ALL), indicate that the average literacy score for Canadians

has not changed significantly in the nine years since the IALS was conducted (Statistics Canada & Organisation for Economic Co-operation and Development, 2005).

If at least one in five Canadians has difficulty with tasks no more complex than the instructions on a medication label, it is likely that health professionals see patients who have limited literacy every day. These professionals ask patients to fill out pre-assessment questionnaires and consent forms. They give patients written material designed to supplement verbal explanations and to remind patients of instructions that may have been misheard or forgotten. If patients cannot decode or understand the material following their contact with the health care provider, health problems may be exacerbated. This may further lower the quality of life of the patient and result in additional treatments and increased costs to the patients and the health care system.

Health care professionals often overestimate a patient's level of reading comprehension and may attribute failure to follow instructions to poor motivation (Bass, Wilson, Griffith, & Barnett, 2002; Osborne, 2001). Patients with limited literacy could be unduly penalized in receiving patient education information because they are often in physically and psychologically vulnerable states due to their illness and the possible feelings of shame of being discovered to have low literacy skills (Parikh, Parker, Nurss, Baker, & Williams, 1996). The result may be that patients are ill equipped to make informed decisions about treatment and prevention of further health problems.

The literacy and health link has just begun to be examined over the last two decades (Rudd, Moeykens, & Colton, 2000). Research in literacy and health has focused on policy issues, program evaluation, and assessment tools (Greenberg, 2001), while the patient education literature has focused on readability of patient education material and increasing the awareness of literacy issues among health care professionals (Osborne, 2001; Perdue &

Degazon, 2001). How adults living with limited literacy and a chronic illness experience patient education has not been investigated. This study attempts to help fill this gap in the literature. In determining a methodology for examining the meaning of patient education to individuals living with chronic illness, it is first necessary to clearly define key terms and describe the context of this experience.

Definition of Terms

Definitions of the following key terms used in this thesis will be presented in this section: chronic illness, patient education, health care professional, limited literacy, and literacy and health. Some of these definitions will be further expanded in the literature review presented in the following chapter.

Chronic Illness

Chronic illness and chronic disease are often used interchangeably in health care research and health care practice. Illness is defined by *The Canadian Oxford Dictionary* as “a disease, ailment, or malady or the state of being ill” (Barber, 2001, p. 705). Disease is similarly defined as “an unhealthy condition of the body or mind; illness or sickness” (p. 399). Disease has also been defined as “a deranged, depraved, or morbid condition” (p. 399). Given that this definition may have a negative connotation for the participants, the word illness will be used exclusively throughout the study.

For this study, chronic illness was broadly defined as any physical condition associated with a decrease in health lasting more than six months, and for which contact had been made with one or more health care professionals. A chronic illness is not a terminal illness; a terminal illness is usually defined as an illness that is expected to lead directly and shortly to death, such as metastatic cancer (Barber, 2001). In this study, the chronic illnesses experienced by the participants included diabetes, arthritis, high blood pressure, and asthma.

Patient Education

Patient education can be defined as any information, advice, or other knowledge that is geared towards helping someone understand and address his or her health problem (Redman, 2004). For this study, patient education included information that health care professionals provided as well as the information that the patients accessed on their own (e.g., health advice from their friends and family). Therefore, patient education included all the different sources of health information and health advice that individuals use in making health-related decisions to manage a chronic illness and is thus viewed as an intervention.

Informal Learning

The expected outcome of any educational intervention is learning. For this study, the learning process of the participants would fall within informal learning. According to Marsick and Watkins (2001), “informal learning is usually intentional but not highly structured” (p. 25). As well, informal learning is “the sort of learning that occurs when people consciously try to learn from their experience” (Foley, 2004, p. 4). How informal learning relates to other types of learning will be expanded upon in chapter 2.

Health Care Professional

For the scope of this study, the term health care professional will be used to describe all of the people working in health care who, in their formal role, are expected to provide patient education while interacting with patients. The general term health care professional will be used throughout the thesis unless the information pertains to one specific health professional group, in which case that professional group will be noted.

Limited Literacy

Literacy has been defined in many different ways over the years. Changes in the conceptualization of literacy will be explored in chapter 2. One key issue to this study

concerns ideas related to grading literacy abilities. While a number of methods for ranking literacy abilities exist, their use has become controversial. Selecting a term to illustrate a person's literacy ability is problematic. As Stercq (1993) observes:

These difficulties of 'name' (literate, semi-literate, functional illiterate through disuse, uneducated, and so on) and 'definition' (and consequently quantification) are not accidental. This population does not exist as such; it is created by the definition of illiteracy chosen, a definition that is always determined by socio-economic and political criteria outside the individual (p. 7).

Keeping these issues in mind, I purposely chose not to assess or test the participants for literacy level. I chose to interview people who had already identified themselves as individuals who had some problems with literacy in that they decided to go to a program with the goal of improving their literacy ability. Although I did not assess the literacy ability of the participants, their literacy ability had been assessed. According to the provincial guidelines that were in place during the data collection phase of this study, the literacy coordinators of each literacy program were required to use a common literacy assessment with all prospective students and establish training plans using learning outcomes. These learning outcomes are based on the IALS' five proficiency levels (Literacy and Basic Skills Section: Workplace Preparation Branch Ministry of Training Colleges and Universities, 2000a). The adult Literacy and Basic Skills (LBS) programs are funded to provide services to adults whose literacy ability is associated to Level 1 or 2 of the IALS (Literacy and Basic Skills Section: Workplace Preparation Branch Ministry of Training Colleges and Universities, 2000b).

Therefore, for this study, limited literacy was defined as the literacy ability of the participants who were attending a community LBS program. Further details and discussion

concerning these common assessments and learning outcomes are found in the education context section of this chapter. Discussion of the properties, application, and implications of the IALS and the ALL will follow in chapter 2 and the explanation of the components of the community LBS programs will be discussed in chapter 3.

Literacy and Health

The World Health Organisation (WHO) has recognized the important relationship between literacy and health in its definition of health literacy (1997):

Health literacy represents 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. Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment (p. 1).

The acknowledgment that health literacy is critical to empowerment has been expanded by Nutbeam (2000) and others (Kickbusch, 2001; Ratzan, 2001; Rootman, 2002). The authors suggest that health literacy should be seen as a public health issue rather than another aspect of literacy. In fact, in Canadian policy papers the term *literacy and health* is used instead of *health literacy* to emphasize the possible connection between literacy and other determinants of health (Canadian Public Health Association, 1997; Health Canada, 2001). For this study, the broader concept of literacy and health was used as a lens in forming the research questions, in the data collection, and in the analysis. This means that health literacy was not seen as a specific set of skills but literacy and health was seen as the processes, settings, and even the values, beliefs, and attitudes associated with various literacy activities used by the participants in trying to deal with their chronic illnesses.

Context of the Study

The study was undertaken in Canada at a time of great flux in both the health care system and the education system. The participants were actively involved with both systems during the period of data collection. To place this study in context, key issues in both areas are discussed below.

Health Care Context

The health care context for this study included not only the interactions of the participants with individual health care providers but also their interaction with the larger health care system in Canada.

There have been many reports over the last few years commissioned by different organizations, including the federal government, that look at the state of the Canadian health care system (Kirby & LeBreton, 2002; Romanow, 2002). Although they all have different emphases and, it can be argued, different political agendas, many common findings have come to light. These include recommendations to invest in primary health care services, improve access to health care services, improve the quality of health care delivery, shift the emphasis from hospital based care to home and community-based care, and focus on health promotion and disease prevention (Kirby & LeBreton, 2002; Romanow, 2002; The Change Foundation, 2005).

The health care system could be defined as the many interdependent but not necessarily interacting individuals, processes, and settings involved in the provision of services to enhance health. One of the stated goals of recent health care restructuring was increased communication and coordination between the multiple providers and across settings (Romanow, 2002). The evidence to date suggests that this goal has not been realized and care may have become, in fact, less coordinated (The Change Foundation, 2005). As

well, at a time when the health care system is becoming increasingly difficult to navigate, Canadians have been encouraged to take on an increasingly greater role in managing their own health care (Romanow, 2002). Patients are often left to their own devices to coordinate the various aspects of their care. For someone with a chronic illness such coordination may include managing considerable amounts of information. For example, people living with a chronic illness may have received information from their family doctors, their specialists, their pharmacists, and possibly other members of the health care team such as nurses. This coordination of information may be particularly challenging for individuals with limited literacy.

The delivery of public health care services is under provincial jurisdiction yet all of the funding for provincial health care comes from the Federal Government through the Canada Health and Social Transfer (CHST) payments (Health Canada, 2005). These transfer payments are based on complicated and ever-changing formulas which determine how much money each province receives in federal funding. Each province in turn makes decisions on where this funding will be allocated, including how much money will go into the public health system which includes such things as teaching hospitals, long term care facilities, and health care professional salaries (Health Canada, 2005). Further variation regarding the provision of specific services exists within each provincial region. Regional contextual factors of relevance to this study will be discussed in chapter 3.

It is estimated that the federal government spent 130 billion dollars on health care in 2004 (Canadian Institute of Health Information, 2005) and the province of Ontario spent approximately \$28.5 billion (Ministry of Health and Long-Term Care, 2005). Chronic disease management is an area of health care spending that is predicted to increase (Canadian Institute of Health Information, 2005). This increase in spending is due to the rise in chronic

illnesses. As the number of Canadians living with chronic illnesses climbs, increased health care dollars will be needed to help people manage these conditions. To reduce this spending and to help Canadians living with chronic illness optimize their quality of life, alliances have been formed at both the national and the provincial levels.

The Chronic Diseases Prevention Alliance of Canada (CDPAC) was formed in 2001 “to help strengthen linkages among established, new, and emerging chronic disease prevention initiatives in Canada” (Chronic Disease Prevention Alliance of Canada, 2005, p. 1). This organization is made up of voluntary health organizations, health professional associations from across Canada, and Health Canada. Similarly in Ontario, the Ontario Chronic Disease Prevention Alliance (OCDPA) was established (Ontario Chronic Disease Prevention Alliance, 2003). The OCDPA is made up of provincial voluntary health organizations, such as the Heart and Stroke Foundation of Ontario and the Ontario Public Health Association.

Both alliances use the WHO’s (World Health Organisation, 2005) definition of disease prevention, which includes primary, secondary, and tertiary prevention. Primary prevention is directed towards preventing the initial occurrence of a disorder. Secondary prevention seeks to arrest or retard existing disease and its effects through early detection and appropriate treatment. Tertiary prevention is aimed at reducing the occurrence of relapses. The policy and practice implications of these alliances as they relate to the findings of this study will be explored in the final chapter of the thesis.

Education Context

The participants in this study were members of adult Literacy and Basic Skills (LBS) programs, a subcomponent of the larger public education system. Similar to health care, adult LBS educational programs are shaped by national, provincial, and even local policy

and funding initiatives. From a federal government perspective, national adult literacy policy directives, at the time of this study, were the responsibility of the National Literacy Secretariat (NLS) which was a part of the department of Human Resource and Skills Development Canada (HRSDC), formerly known as the department of Human Resources and Development Canada (HRDC). The NLS's key initiatives were in the areas of "partnership development, project development and consultation, grants and contributions, support of promotion and awareness of materials and events, research, policy analysis, symposia and consultative meetings" (Government of Canada, 2005, para. 1). The NLS's initiatives worked to improve adult literacy and to promote public awareness of the issue of literacy in Canada. The NLS did not directly fund the delivery of literacy programs. The NLS partnered with the provinces, territories, non-government organization, and business and labour organization to coordinate research and increase awareness of literacy (Government of Canada, 2005).

The LBS programs in Ontario have traditionally been funded through the Ministry of Education. In recent years, due to the fact that there has been an increased emphasis in these programs on training and skill acquisition geared to employment preparation, the funding is now provided by the Ontario Ministry of Training, Colleges and Universities (MTCU) (Literacy and Basic Skills Section: Workplace Preparation Branch Ministry of Training Colleges and Universities, 2000b). In Ontario, LBS programs are offered by school boards, community colleges, and non-governmental organizations, such Frontier College, as well as within work environments (Ontario Literacy Coalition, 2005).

Regardless of the setting, all provincial funded LBS programs in Ontario are mandated by the province to use common assessment policies and procedures. These policies and procedures do not include the use of one common assessment tool, but the use of

assessment tools and approaches that are compatible across all LBS programs (Literacy and Basic Skills Section: Workplace Preparation Branch Ministry of Training Colleges and Universities, 2000a, p. 1). Some of the reasoning behind a common assessment approach is to allow learners to seamlessly move from one program to another and to allow for comparison among programs.

The common assessment framework provides the basis for the development of an individualized training plan for each learner (Literacy and Basic Skills Section: Workplace Preparation Branch Ministry of Training Colleges and Universities, 2000c). The training plans are established using a learning outcomes matrix. At the time of this study, these learning outcomes for literacy were based on the learning outcomes from the Ontario Elementary School Curriculum, grades one to eight, from 1997 (Literacy and Basic Skills Section: Workplace Preparation Branch Ministry of Training Colleges and Universities, 1998, p. 1). The intent of having specific outcomes is to:

focus attention on the ability of learners to apply the learning that has taken place in settings and situations related to their goals. The attention is paid to application also supports and accommodates a goal-directed, learner-centred approach to instruction (Literacy and Basic Skills Section: Workplace Preparation Branch Ministry of Training Colleges and Universities, 1998, p. 4).

These learning outcome domains are communication, numeracy, self-management, and self-direction. Each domain has five levels (see Table 1). These levels are also linked with the IALS levels also noted in Table 1 (Literacy and Basic Skills Section: Workplace Preparation Branch Ministry of Training Colleges and Universities, 1998, p. 17).

Table 1

Learning Outcome Matrix

IALS Level	Learning Outcome Matrix
Prose Literacy 1	Communication Levels 1-3
Prose Literacy 2	Communication Levels 4-5
Document Literacy 1	Communication Levels 1-3
Document Literacy 2	Communication Levels 4-5
Quantitative Literacy 1	Numeracy Levels 1-3
Quantitative Literacy 2	Numeracy Levels 4-5

The above levels are also linked with the federal governments' Human Resource and Development Canada (HRDC) essential skills (Literacy and Basic Skills Section: Workplace Preparation Branch Ministry of Training Colleges and Universities, 1998, p. 17). These essential skills were established through a research project, to find the common "skills needed in virtually all occupations and facets of life" (Human Resources and Skills Development Canada, 2005, para. 1). There are nine essential skills: reading text, document use, numeracy, writing, oral communication, working with others, continuous learning, thinking skills, and computer use (Literacy and Basic Skills Section: Workplace Preparation Branch Ministry of Training Colleges and Universities, 1998, p. 17).

To help literacy practitioners understand the specific items for each of the learning outcome levels, the Ontario Literacy Coalition (OLC) produced *The Level Descriptions Manual* (2001), with funding from the NLS and the MTCU. The OLC's mandate is to provide the Ontario literacy community with a "forum to encourage ongoing networking and

cooperation between literacy programs, providers, and learners” (Ontario Literacy Coalition, 2005, para. 2). The OLC’s manual describes each level of the learning outcome matrix with specific examples. Literacy practitioners are encouraged to use the level descriptions to identify the needs of each learner. Learners’ needs are related to their skills and goals at the time of assessment. The result is that each adult learner has an individualized training plan even though the learner is also a member of a LBS classroom and participates in common activities with the other learners. Further discussion of the specifics of the LBS programs can be found in chapter 3 under the subheading setting.

Now that key terms have been defined and an overview of the context has been described, the organization of the proceeding chapters will next be outlined. Chapter 2 will provide the academic background for the study. It contains a literature review dealing with the main topic areas of literacy, literacy and health, patient education, and three adult learning theories: transformational learning, situated cognition, and critical theory. In chapter 3, the research methodology of this study is described including the research approach taken, research design, data collection, procedure, and tools. Finally, trustworthiness of the research will be discussed.

Chapter 4 will present a profile of each of the participants including their characteristics and the findings from the demographic form. The profiles will help the reader gain a better understanding of the participants that informed this study. This chapter will also discuss the research findings which are divided into the main categories and themes that emerged from the data. Chapter 5 presents an interpretation of the findings that are supported with quotes from the participants as well as links to the current literature including adult learning theories. Finally, chapter 6 summarizes the research findings and discusses contributions of the study findings to theory, practice, and policy.

CHAPTER TWO- LITERATURE REVIEW

A literature review was undertaken to place this study in context. First, research and theoretical literature relating to adult literacy, literacy and health, and patient education was identified through searches of the following databases: Cancer, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Dissertations and Abstracts, Educational Resources Information Centre (ERIC), EMBASE, MEDLINE, MLA International Bibliography, PsycInfo, and Sociofile. The subject headings that were searched included: communication, chronic illness, health advice, health care communication, health information, health literacy, illiteracy, language, literacy, literacy and health, patient education, reading, and readability. The literature was critically reviewed and synthesized.

The literature review in phenomenology is used to specify important variables that can serve as a background to meanings of the hermeneutic analysis (Koch, 1995; van Manen, 1997b). This chapter provides the background for the study and contains literature dealing with the main topic areas of literacy: literacy and health and patient education. As well, because the focus of the research is on patient education experiences, adult learning theories are also included.

Literacy

This section of the literature review presents issues within the field of literacy including descriptions of literacy. As well, two major studies of literacy of Canadians, the IALS and the ALL, will be discussed in detail to help the reader understand the extent of the issue of limited literacy in Canada and internationally. These two studies are presented because they are the key assessment tools that have informed literacy practice, policy and research over the last decade. The results allow the reader to identify Canada's results within

its relationship to the world. Finally, other major research areas in literacy will be briefly reviewed. These different aspects of the field of literacy are presented in detail to introduce readers who may not be aware of these areas of study. A better understanding of literacy is important for the reader to recognize the need for this study and how it fits into other literacy studies. This information will also be important to understand the implications of the findings in terms of literacy policy and practice which will be presented in Chapter 6.

Descriptions of literacy

Descriptions of literacy have gone through significant alterations over the last few decades. New descriptions of literacy have been added including a school-based definition, a functional definition of literacy, a sociocultural/constructivist view, and finally, a concept of critical literacy. Presently, there is not one definition or approach that has universal agreement and acceptance. Therefore, the following four depictions will be reviewed.

School-based. A school-based model of literacy attempts to fit adult literacy within the same conceptual framework of that used in children's literacy. Here, the literacy ability levels equate with grade levels found in schools. These grade levels are used to describe literacy in terms of reading and writing. These models are used in many readability formulas and assessment tools (Doak, Doak, & Root, 1996).

One criticism of this definition is its reliance on a framework used in children's learning that ignores the fact that adults learn differently than children and therefore the same learning concepts cannot be applied (Merriam & Caffarella, 1999). Knowles (1975) noted that the focus of adult learning is directed towards solving problems in everyday life. Adults use their previous experiences as learning resources when in a new learning situation. Adults will modify knowledge gained in previous experiences and transfer this knowledge to the new situation. In the case of children, learning is focused on building new skills and

acquiring new knowledge. Unlike adults, however, children do not possess years of life experience to draw upon as learning resources; they must gather new information to apply to the present situation.

Another criticism of this model is that it equates literacy with the contextless ability to read. Thus, recognition of the greater complexity of literacy led to the development of the concept of functional literacy.

Functional literacy. A definition of functional literacy is based on the belief that people need and apply different sets of literacy skills in the different contexts of their lives. For example, a person uses one set of literacy skills at work and another set at home. Functional literacy comprises the information processing skills needed to use printed material in everyday contexts such as work, home, and community (Fingeret & Drennon, 1997).

Functional literacy certainly provides a broader concept of literacy, and one that is more relevant to adults. It appears, however, to consider literacy contexts as fairly similar and static, the literacy skills in situations are not affected by social interactions. A sociocultural/constructivist concept of literacy addresses this limitation.

Sociocultural/constructivist description. From a sociocultural/constructivist view, literacy practices exist “in the relations between people, within groups and communities, rather than as a set of properties residing in individuals” (Barton, Hamilton, & Ivanic, 2000, p. 8). This moves the description away from basic skills of the learner as applied to a specific function, to a concept of literacy activities that become meaningful due to the interaction with society.

Critical literacy. Critical literacy takes the sociocultural/constructivist description to a level of empowerment, allowing the learner to become a full participant in society. Critical

literacy is defined as “more advanced cognitive skills which, together with social skills, can be applied to critically analyze information, and to use this information to exert greater control over life events and situations” (Nutbeam, 2000, p. 238). Critical literacy allows an individual to take part in the power structure of his or her society.

Some of these different definitions of literacy have influenced assessment practices and public policy (Askov, 2001). For example, a functional definition of literacy has been used as a basis for establishing literacy levels or prevalence rates of literacy for populations by using a survey.

Canadian Literacy Surveys

The literacy survey that has probably had the greatest impact on literacy practice, and on public recognition of the issue of literacy, is the IALS (Statistics Canada & Organisation for Economic Cooperation and Development, 1995). The IALS survey was followed by the ALL. The IALS and the follow up study of the ALL will be discussed in the next sections. These sections will include the definitions of literacy used, how the surveys were completed, results, and concerns about the surveys.

International Adult Literacy Survey (IALS)

The IALS was commissioned in 1994 by the Organisation for Economic Co-operation and Development (OECD) to help obtain data to understand the relationship of adult literacy levels to economic competitiveness (Statistics Canada & Organisation for Economic Cooperation and Development, 1995). The IALS was formed using the conceptual framework and methodology of the Young Adult Literacy Survey (YALS) conducted in the United States in 1985, and the National Adult Literacy Survey (NALS) conducted in the United States in 1993 (Statistics Canada & Organisation for Economic Cooperation and Development, 1995). The original seven countries included in the IALS were Canada

(English and French), Germany, the Netherlands, Poland, Sweden, and Switzerland (French and German). The data for the United States came from the NALS.

Literacy was defined as “a mode of adult behaviour, namely using printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential” (Statistics Canada & Organisation for Economic Cooperation and Development, 1995, p. 14). The IALS was conducted using a door-to-door survey of people aged 16 to 65, with a sampling proportion from .0019 % of the population in the United States to .049 % in Sweden. In Canada, .022% of English speaking Canadians and .029% of French speaking Canadians were surveyed (Statistics Canada & Organisation for Economic Cooperation and Development, 1995, p. 15).

Measurement of literacy. Literacy skill level was measured using two different scales: A self-assessment scale and a performance task scale. In the self-assessment scale, participants were asked how well their reading, writing, and numeracy skills met their needs in their daily lives and work (Statistics Canada & Organisation for Economic Cooperation and Development, 1995). The performance task scales consisted of three literacy scales: prose, quantitative, and document. The task levels were determined using simulation of real life tasks. The range of scores for each scale was 0 to 500. The range of scores was divided into five levels from the lowest level (Level 1) to the highest level (Level 5). The specific scores for each level were: Level 1 (0-225), Level 2 (226-275), Level 3 (276-325), Level 4 (326-375), and Level 5 (376-500) (Statistics Canada & Organisation for Economic Cooperation and Development, 1995, p. 28).

Prose literacy. Prose literacy was defined as the “knowledge and skills needed to understand and use information from texts including editorials, news stories, poems and fiction” (Statistics Canada & Organisation for Economic Cooperation and Development,

1995, p. 14). An example of a task from Level 1 “is looking at a medicine label to determine the maximum number of days you should take this medicine” (Statistics Canada & Organisation for Economic Cooperation and Development, 1995, p. 31).

Quantitative literacy. Quantitative literacy was defined as “the knowledge and skills required to apply arithmetic operations, either alone or sequentially, to numbers embedded in printed materials, such as balancing a cheque-book, figuring out a tip, completing an order form or determining the amount of interest on a loan from an advertisement. An example of task from Level 2 is “looking at a weather chart in a newspaper to determine how many degrees warmer today's temperature is expected to be in Bangkok than in Seoul” (Statistics Canada & Organisation for Economic Cooperation and Development, 1995, p. 44).

Document literacy. Document literacy was defined as “the knowledge and skills required to locate and use information contained in various formats, including job applications, payroll forms, transportation schedules, maps, tables and graphics” (Statistics Canada & Organisation for Economic Cooperation and Development, 1995). An example of a document literacy task from Level 3 “is looking at a bus schedule to determine the time of the last bus that you could take from a particular location on a Saturday night” (Statistics Canada & Organisation for Economic Cooperation and Development, 1995, p. 40).

The results of the IALS have been used in numerous national and international reports. The main Canadian reports are *Literacy, Economy and Society* (Statistics Canada & Organisation for Economic Cooperation and Development, 1995), *Reading the Future: A Portrait of Literacy in Canada* (Statistics Canada et al., 1996), the *Second Report of the International Adult Literacy Survey (IALS): Literacy Skills for the Knowledge Society* (Statistics Canada, Human Resources Development Canada, National Literacy Secretariat, & Organisation for Economic Cooperation and Development, 1997), and the *Final Report of*

the International Adult Literacy Survey (IALS): Literacy in the Information Age, Skills for the 21st Century (Statistics Canada, Human Resources Development Canada, National Literacy Secretariat, & Organisation for Economic Cooperation and Development, 2000). All the reports recognized that while most people can read, the real question is whether their literacy skills meet the challenge of living and working in today's society.

The reports note relationships between literacy levels and demographic characteristics, such as education, employment, age, gender, and income. The IALS, for example, found that participants in lower socioeconomic levels also had lower literacy levels. The IALS results from the original seven countries surveyed, including the NAL results for the United States, in the three domains of prose, document and quantitative for Level 1 and Level 2 are presented in Table 2 (Statistics Canada et al., 1996, p. 33; Statistics Canada et al., 1997, p. 151). Canadian participants had the choice of completing the survey in either English or French; 3,130 participants completed the survey in English and 1,370 participants chose to do the survey in French (Statistics Canada & Organisation for Economic Cooperation and Development, 1995, p. 15). Table 2 allows the reader to visually compare the prose, document, and quantitative level 1 and 2 across the different countries. As noted in Table 2, there is a large gap in the percentage of English and French participants in Level 1. The percentages across all three domains are very similar for Level 1 and 2 for the English respondents from Canada and are relatively close to the results of the respondents from the Netherlands and Germany. These two countries had the lowest percentage of respondents in Level 1 and 2. In contrast, Poland had the largest percentage of respondents across the three domains. In terms of the comparison between the combined French and English respondents from Canada and the respondents from the United States,

the overall percentages are very similar with the Canadian percentage slightly less in Level 1 across the three domains and almost identical for Level 2.

Table 2

IALS- Percentage of Respondents in Lower Literacy Levels

Country	Prose Level 1	Prose Level 2	Document Level 1	Document Level 2	Quantitative Level 1	Quantitative Level 2
Canada English	13	25	15	23	14	23
Canada French	25	27	28	28	25	32
Canada Combined Eng/French	16.6	25.6	18.2	24.7	16.9	26.1
Germany	14.4	34.2	9.0	32.7	6.7	26.6
The Netherlands	10.5	30.1	10.1	25.7	10.3	25.5
Poland	42.6	34.5	45.4	30.7	39.1	30.1
Switzerland French	17.6	33.7	16.2	28.8	12.9	24.5
Switzerland German	19.3	35.7	18.1	29.1	14.2	26.2
United States	20.7	25.9	23.7	5.9	21.0	25.3

There are many concerns with both the methodology and the underlying conceptual framework of the IALS, including the validity of the IALS results and the criticism of the conceptual framework used to guide the design of the survey. These concerns are outlined by Sticht (2001) and revolve around construct validity, possible classification errors, and face validity.

Sticht questioned the construct validity of the IALS since its performance scales are based on a theory of reading, not adult literacy. That is, the IALS dealt with information

processes, skills, and cognitive ability but did not look at prior knowledge. In addition, “there is no explicit discussion of a cognitive theory of the competence (knowledge and skills) that adults must possess to be able to perform the many tasks” (Sticht, 2001, p. 24). There are also concerns that the prose, document, and quantitative scales are not distinct items as they have strong correlations (.90) with each other and therefore do not measure different skills. Finally, within the self-assessment component of the survey, there were no specific definitions or criteria for reading, writing, and numeracy skills for the participants to use as reference points. This may indicate that people with limited literacy avoid activities which they know they cannot accomplish because of their limited literacy and therefore do not attempt the activity. People in these situations might then report a strong self-assessment of their literacy ability because their literacy ability is more than adequate for their daily activities.

The results of the IALS are further questioned because of the possibility of classification errors related to the cutoff scores used to define literacy levels. Participants were placed in a level if, based on their full score, they had an 80% probability of being able to complete the average task in that level. Such a high probability can lead to a high false negative rate; that is, it may result in a large number of people being categorized in a group lower than what they were actually capable of doing.

The use of face validity, or how the results from the test appeared from a public point of view, is also a concern. When the results of the NALS were published in the United States, there were “negative social consequences” (Sticht, 2001, p. 28) due to 48% of the population being categorized in the two lowest literacy skill levels. The results seemed so unbelievable that they were discounted and limited action was taken on a policy level. Despite these criticisms and the concern that the IALS represents only a partial and

simplistic view of literacy that does not take into consideration the complex use of literacy in people's lives (Hamilton & Barton, 2000, p. 380), findings of the IALS have influenced Canadian literacy policy and practice. For example, as mentioned above, the IALS levels form the basis for evaluation tools, including the Learning Outcome Matrix (1998) which is used in all Ontario provincially funded literacy programs. Nationally, the IALS levels are used as the benchmark to determine the success of literacy programs (Government of Canada, 2005; Sussman, 2003).

International Adult Literacy and Life Skills Survey (IALSS)

The most recent national adult literacy survey conducted in Canada was the International Adult Literacy and Life Skills Survey (IALSS) conducted in 2003. The IALSS builds on the methods of the IALS and is the Canadian component of the Adult Literacy and Lifeskills Survey (ALL), an international survey (Statistics Canada & Organisation for Economic Co-operation and Development, 2005). Statistics Canada made the decision to use the IALSS name in its publications and in other Canadian governmental reports. It is thought that, given the similarities of the acronyms IALSS and IALS, audiences will quickly associate the two surveys. The IALSS builds on the IALS and has many similarities with the previous study. The literacy measurement, definitions, methodology, and results of the IALSS are outlined below.

Three reports relevant to the IALSS were published in 2005. The international findings of the ALL are found in a report jointly published by Statistics Canada and the OECD: *Learning a living: First results of the adult literacy and life skills survey*. The first Canadian report published by Statistics Canada was the *International adult literacy survey: Measuring adult literacy and life skills: New frameworks for assessment* in March 2005. The

second, *Building on our competencies: Canadian results of the International Adult Literacy and Skills Survey* was published in November 2005.

Measurement of literacy. The areas of literacy competency measured in the IALSS were prose, document, numeracy, and problem solving. Prose and document literacy were defined in the same way as they were in the IALS. However, the term “numeracy” rather than “quantitative literacy” was used to indicate concern with a broader construct than knowledge of arithmetic. Numeracy was defined as “the knowledge and skills required to effectively manage the mathematical demands of diverse situations” (Statistics Canada & Organisation for Economic Co-operation and Development, 2005, p. 16). An example of a Level 1 task involved looking at a short text that showed the results of an election involving three candidates and determining the total number of votes cast.

Similar to the IALS, the domains of prose literacy, document literacy and numeracy were rated using 0 to 500 point scales; point scores were then used to classify literacy in five levels of proficiency. The decision was made, because of the small number of respondents in Level 5, to combine results from Levels 4 and 5 (Statistics Canada, 2005b, para. 10).

A new category, problem solving, was added to this survey. This category was added to capture how adults actually use literacy skills in dealing with the everyday problems that they encounter. The operational definition was that

problem solving involves goal-directed thinking and action in situations for which no routine solution procedure is available. The problem solver has a more or less well defined goal, but does not immediately know how to reach it. The incongruence of goals and admissible operators constitutes a problem. The understanding of the problem situation and its step-by-step transformation, based on planning and

reasoning, constitute the process of problem solving (Statistics Canada & Organisation for Economic Co-operation and Development, 2005, p. 16).

An example of a problem solving task involved setting the date for a family reunion in July and organizing the components of a hike as an activity on the day of the reunion. This task was used as an example in ALL publications, but was not actually used with participants in the final ALL. The task is introduced in a paragraph explaining that family members have multiple appointments in July, so the first step of the project is to set a common date when everyone can attend the reunion. The second step of the problem solving task is to consider the relatives' suggestions for the hike. There are seven components of the project that the respondent needs to consider (Statistics Canada & Organisation for Economic Co-operation and Development, 2005, p. 222). The problem solving domain was scored similarly to the other three domains of literacy. That is, responses were scored using a 0 to 500 point scale; this score was then used to classify literacy within one of four categories.

Methodology. The countries or areas of the world surveyed were Bermuda, Canada, Italy, Norway, the Mexican State of Nuevo, Switzerland, and the United States. In Canada, 23,000 individuals between the ages of 16 to 65 representing .09% of the population were surveyed. This was approximately four times the proportion sampled in the IALS. The survey was conducted from March to September 2003.

Concerns existed that the IALS sample did not reflect all Canadians given that it did not, for example, include people living in the territories. To improve on this aspect of the IALS methods, the IALSS drew its sample from the Census of Population and Housing databases as of May 15, 2001 (Statistics Canada, 2005b, p. 230). This sampling was used to increase the probability that all members of society would be represented. In the end, the sample included 3,400 Aboriginal Canadians, 2,600 established immigrants (10 years or

more in Canada), 1,200 recent immigrants (less than 10 years in Canada), 3,500 Francophones outside of Quebec, and 3,500 youth ages 16 to 24 years old. There were 15,694 respondents who responded to the survey in English and 4,365 who completed the survey in French.

Similarly to the IALS, demographic information, age, gender, language, ethnocultural background, immigration history, education, employment status, and living location/geography was collected from each participant. All of these factors were analyzed in relation to the literacy results.

One area that many people felt was missing from the IALS was a measure of health status. This measure would have allowed for a comparison between health status and literacy ability. Therefore, the developers of the IALSS, in recognition of this potentially important area, included a self-report quality of life tool, the SF-12. This reliable and valid tool is a modification of the original SF-36. The SF-36 is viewed as the gold standard of health-related quality of life survey measures (McDowell & Newell, 1987). The 12 questions of the SF-12 capture 90% of the variance of the SF-36. This version is often used for large studies because of its shorter administration time (The SF Community, 2005). Two subscales are produced by the tool: The Physical Component Summary (PCS-12) and the Mental Component Summary (MCS-12) (Statistics Canada, 2005b, p. 92). The two subscales were used to categorize the health of respondents as poor, fair, good, or excellent using latent class analysis. An example of a question from the SF-12 is, does your health limit climbing stairs? The options for answers were: Yes, limited a lot; yes, limited a little; no, not at all limited, or the participants had the option to indicate that they refused to answer the question or the answer was not stated.

From the results of the IALSS and the ALL, it appears that prose and document literacy in Canada (combined French and English) and the United States (Statistics Canada & Organisation for Economic Co-operation and Development, 2005) have not substantially changed since the IALS and NAL surveys in the mid 1990's (Statistics Canada et al., 1997). The percentage of respondents in the five levels of the domains of prose and document for Canadian and American respondents can be found in Table 3. Table 3 is provided to help the reader compare the levels of prose and document literacy between Canada and the United States and to note changes from the IALS to the ALL/IALSS administration. Understanding the similarity and differences in results will help the reader when reading the next section of the literature review, the literacy and health section. In this next section the majority of the studies discussed were completed in the United States, at times using information from the IALS and ALL data.

It is interesting to note that the percentage of the respondents in Level 1 and Level 4/5 has slightly decreased for the domain of prose and document while the percentage of respondents in Level 2 and 3 have increased for both countries, resulting in the largest percentage of respondents falling into Level 3.

Table 3

Comparison of Canadians and Americans Literacy Levels

Survey	Canada		United States	
	IALS	ALL/IALSS	NAL	ALL
Prose Level 1	16.6	14.6	20.7	20.0
Prose Level 2	25.6	27.3	25.9	32.6
Prose Level 3	35.1	38.6	32.4	34.6
Prose Level 4/5	22.7	19.5	21.1	12.8
Document Level 1	18.2	15.6	23.7	20.2
Document Level 2	24.7	27.0	25.9	32.3
Document Level 3	32.1	36.9	31.4	32.6
Document Level 4/5	25.1	20.5	19.0	15.0

Table 4 allows the reader to compare the results of numeracy between Canada and the United States as well as the results for Canada of the new domain of problem solving. It is interesting to note, that similar to the domains revealed in Table 3, literacy levels among Canadians and Americans were also similar in the new literacy domain of numeracy.

Table 4

Comparison of Canadian and American Percentages for Numeracy

	Canadians	Americans
Numeracy Level 1	19.5	26.8
Numeracy Level 2	30.3	31.8
Numeracy Level 3	33.4	28.8
Numeracy Level 4/5	16.9	12.7
Problem Solving Level 1	29.7	n/a
Problem Solving Level 2	38.8	n/a
Problem Solving Level 3	26.2	n/a
Problem Solving Level 4/5	5.4	n/a

Within the domain of numeracy, the majority of respondents were in either Level 2 or Level 3 for both countries. The United States did not survey the problem solving domain (Statistics Canada & Organisation for Economic Co-operation and Development, 2005, p. 50). In terms of problem solving, the largest percentage of Canadian respondents was found in Level 2.

To determine the relationship between literacy and health for the IALSS, the authors compared the results from the document literacy domain with the self-reported quality of life tool, the SF-12. The document domain was selected by the authors because they felt that “health care instructions and directions for taking medications typically correspond to the general competencies measured by document literacy” (Statistics Canada, 2005b, p. 92).

The relationship between document literacy and health status demonstrates that low literacy scores are associated with poorer physical health. The average document literacy for the group that reported their physical health as poor was Level 2. There did not appear to be an association between mental health and document literacy. However, it should be noted that these findings are the result of a relatively simple examination of the relationships between these variables. The document literacy domain is certainly not the only domain that may be related to health status results. The numeracy domain could also be related to health status due to the fact that taking medication correctly also involves numbers, such as dosage and time of medication. It is hoped that policy and funding decisions will not be made before more detailed analyses are completed. It is also hoped that future reports of the IALSS findings will include results of the analyses of the potential relationship between the domains of numeracy, problem solving, and health status.

As the initial reports and findings of the ALL/IALSS are published, many concerns are being raised that are similar to those identified for the IALS publication. Sticht (2005) has also expressed his concerns about the validity of the ALL. In a recent publication he again questioned the use of the 80% probability of success with each proficiency level as the cut-off point for classification of literacy level (Sticht, 2005). The cut-off is a concern because, again, the results indicate that a large percentage of adults in Canada and the United States are in Level 1 and 2. Once more, these numbers are so large that the results lack face validity. It is unlikely that people will believe, for example, that 8.9 million Canadians are at Level 1 or 2 (Statistics Canada & Organisation for Economic Co-operation and Development, 2005). As well, Sticht (2005) continues to be concerned that the ALL still draws on the practice of “unsupported inferences about the levels of literacy needed by adults to meet the demands of contemporary societies” (para. 8). He is concerned that the

preliminary reports from the ALL's results equate Level 3 results in the different domains with the ability to cope with daily literacy demands. The authors of the survey do not appear to have a justification for using this level opposed to another level in the survey.

The IALS and the ALL/IALSS are, without doubt, the largest and most well-know adult literacy surveys. While the prevalence of different levels of literacy capability in Canada has been examined in these studies, there are other issues related to literacy that have also been studied by Canadian researchers. This other research is reviewed below to help place the study within the context of current literacy research in Canada

Research in Literacy

Campbell (2004) reviewed the last decade of Canadian literacy research publications noting ten different themes. In decreasing order of number of publications, these were family literacy, access and retention, educators and students, literacy and the labour market, programs, workplace education, learning, technology, health, and reading and writing. Although Campbell also noted that there were certain gaps in the research areas, including "Aboriginal literacy programs and learners; assessment practices; and the history of adult literacy" (p. 44), she believes that a lot has been accomplished.

Research in family literacy has included investigations of intergenerational literacy programs. These programs incorporate the unique issues of looking at literacy in the context that adults are also part of family units. In intergenerational programs, family members, parents and children, who might have different levels of literacy, are all taught together (Taylor, 2001, p. 173).

Access and retention research has also been quite extensive. The aim of much of this research is to try to understand the reasons why adults enter or do not enter literacy programs and why individuals leave these programs. ABC CANADA, a national literacy organization,

is one such example of more recent research that is conducted with the purpose of gaining some understanding of these issues and that makes relevant changes in their program delivery (Long, 2002).

Research related to educators and students consists of a large range of topics, including both educators' and students' experiences in the literacy field. Research in this area has included investigations of the goals, perceptions, and practices of students and educators.

Literacy and the labour market research relates primarily to studies that have used the results of the IALS. The main reason behind the commissioning of the IALS was to gain data that might help shed light on the relationship between adult literacy levels and economic competitiveness. The research in this area tracks the realities of individual learners as they work to improve their literacy abilities, and notes the relationship between literacy and employment. For example, Malicky and Norman (as cited in Campbell, 2004) carried out a longitudinal study that revealed that "most learners returned to the same type of low-paying temporary work that they had done before enrolling in literacy classes" (p. 43).

Program research has investigated adult literacy and basic education within different contexts, including correctional programs, community programs, and employment preparation programs. Workplace education research concerns investigation of literacy interventions carried out in the workplace. Theoretical framing of this research has been dependent on the focus of the interventions. If the intent of the workplace education program is an increase in productivity as a result of improved literacy skills, then economic theories have been used to develop the research questions, choose the assessment or outcome tools, and even determine the statistical analyses. For example, a long-term workplace education project that was carried out by Wiebe (2001) linked literacy instruction with existing technical training at an aerospace community in Winnipeg, Manitoba. The economic

outcomes used were cost-benefit analysis, quality standards, quality assurance, and productivity.

Literacy research related to learning has investigated how adults learn literacy skills. This research has led to new ways of the thinking about learning that take into consideration the complexity of adults' lives. Researchers in this area have also applied theoretical frameworks to try to understand relationships, contexts, and meanings for adults learning in a literacy class. For example, Taylor and Blunt (2001) used the theory of situated cognition to develop a grounded theory of adult literacy. When adult literacy learning is viewed through the lens of social and cultural relationships, the way learners draw upon events from their ordinary lives to construct meaning within communities is revealed. Literacy is a social-cultural process where one becomes literate within a social context as an extension of relationships with other people (Kirshner & Whitson, 1997). One type of research approach that has accomplished this objective is called The New Literacy Studies. There are two assumptions to this approach: (1) that literacy practices are socially embedded and cannot be understood in isolation and (2) that the objective of literacy studies is "literacies" in various social situations rather than one literacy (Ewing, 2003).

Technology research examines issues related to literacy and technology. The areas of technology that have been considered fall into three categories. According to Campbell (2004) the three categories include software, students and programs. This area of research also includes the new work which explores the use of computers as teaching tools, such as elearning.

Research related to literacy and health was the ninth most popular area of research in Campbell's review. Much of the literature in this area describes research policy initiatives rather than the findings of actual research studies carried out in Canada. Due to the paucity of

literature in the area of health, the Canadian Public Health Association and the University of Toronto's Centre for health promotion have been working on the establishment of a national program for literacy and health research (Rootman, 2002).

It is somewhat surprising that research related to Reading and Writing was the tenth area of research publications. Since reading and writing appear to form the basis of literacy, one might expect that research in this area would be greater. Campbell (2004) proposed that the dearth of research in this area in the past decade might be due to the fact that researchers are aware of the difficulty in trying to untangle the different elements of reading and writing and therefore do not pursue these lines of inquiry.

These ten different areas of research could be categorized into practice-based research, looking at applications used by literacy practitioners, and academic-based research, investigating the theoretical basis of issues in literacy. However, this traditional division of research has been seen by both sides as having little benefit for the overall field of adult literacy. Therefore, there have been attempts to combine both types of orientations in a single research program. Research in Practice in Adult Literacy (RiPAL) groups have been established in the last decade in a number of provinces such as British Columbia (Alkenbrack, Middleton, Niks, & Soroake, 2003) and Alberta (Norton, 2003). Their aim is to link research with practice and to support practitioners who would like to engage in research. Their research has focused on issues that could be categorized as non-formal, non-academic projects that actively involve learners as full participants (Alkenbrack, 2004).

More traditional academic research initiatives have continued as well. Three theories have been proposed in the literature to inform literacy studies and literacy teaching. These are the literacy-as-practice model, functional context theory, and the participatory model of literacy. The literacy-as-practice model, developed by Fingeret and Drennon (1997),

conceptualizes literacy as a set of social practices that can lead to a “literacy identity.” They believe that literacy should be linked to life improvement for the participants in literacy programs. The students that they have studied felt that their personal journeys of discovery in becoming more literate were just as important as the end result. These journeys involved the students gaining confidence and recognition of important cultural symbols surrounding literacy. Fingeret and Drennon’s literacy-in-practice model is seen as “a developmental model which tries to explain the shift from orality to literacy in the reconstruction of an adult identity” (Demetrian, 2001, p. 108).

Sticht's (1997) functional context theory can be used in a setting where the learning objectives are related to very specific types of information, as is often seen in workplace literacy programs (Demetrian, 2001). According to Sticht (1997) “literacy is developed while it is being applied” (p. 2). The cognitive approach underlying the theory focuses on the mastery of tasks viewed as essential for life adjustment. Using this cognitive approach, students receive an explanation of what they are to “learn and why so that they can always understand both the immediate and long term usefulness of the course content” (Sticht, 1997, p. 3).

In the development of the participatory approach to literacy, Auerbach (1989; 1992) built on the work of Freire (1970). In this theory, literacy is viewed as “a social issue linked to class, race, and gender oppression” (Auerbach, 1992, p. 71). This model has special applicability in programs linked to community-based agencies that promote social change and empowerment through critical-reflection and collaborative action (Demetrian, 2001).

Summary of the Literature Review of Literacy

Descriptions of literacy were discussed within this section of the literature review. These descriptions were included to broaden the reader’s understanding that literacy is not

just reading and writing but is much more complex. As we have seen, some of these descriptions of literacy have had an influence on the definitions, methodology, and results of the IALS and the ALL. The IALS and the ALL survey results were presented to help the reader understand the scope of the issue within Canada and in the world. Even though there are significant concerns with these assessment tools, they continue to have an influence on literacy practice, policy, and research. Other major areas of research in adult literacy were also discussed to situate the study in the context of literacy research in Canada and to have a greater understanding of the scope of the field of literacy research. From this discussion, it is apparent that literacy is a complex phenomenon; it cannot be simply viewed as a dichotomy of literacy versus illiteracy. Any examination of literacy must allow for the consideration that it represents a continually changing set of abilities that are reflective of context, needs, and expectations. Literacy therefore encompasses more than a specific set of skills, and may be best understood, as Darville (1999) has suggested, as a conceptual construction. Literacy is both a concept and a construction, reflective of different needs and expectations in social practices. One social practice for most adults is interacting with the health care system. Literacy expectations in the health care system are continually increasing. This is partly due to the fact that Canadians are being encouraged and expected to take more responsibility for their health (Romanow, 2002). Consequently, many adults are in the process of trying to find, understand, and integrate information that they have never previously had to use. Some of these attempts to learn more about their health and health concerns involve patient education experiences.

Patient Education

A conceptualization of patient education will now be discussed as well as different aspects of patient education including health promotion, disease prevention, risk factor

modification, and illness management. The specific aspects of patient education geared towards management of chronic illnesses will also be discussed including behaviour modification and development of skills and knowledge. The purpose of this section is to expose readers who may be new to the area of patient education geared towards chronic illness management and to situate the present study within the context of current patient education practice and research.

Conceptualization of Patient Education

A framework is provided to place patient education in the broader adult education field. Different authors have conceptualized adult education in recent years to try to establish a common framework for an often confusing and fragmented field (Foley, 2004; Livingstone, 1999; Schugurensky, 2000). Schugurensky (2000) has suggested three categories of adult education including, formal adult education, nonformal education, and informal learning. Formal education is conducted in an institute such as a secondary school or a university. There is a ladder system in place within the institute, that is, the learner must complete a number of stages consecutively. Certification diplomas and university degrees are examples of outcomes of formal education.

Nonformal education includes “all organized educational programs that take place outside the formal school system, and are usually short-term and voluntary” (Schugurensky, 2000, p. 2). Patient education provided by health care professionals using planned educational sessions, such as nutrition classes on preparing meals for someone who has diabetes, could be categorized as nonformal education.

Patient education that is not carried out in this type of structured format would be categorized as informal. Informal learning takes place outside of the curricula provided by either the formal or nonformal education programs (Schugurensky, 2000, p. 2).

Schugurensky (2000) has postulated that informal learning can take on three different forms: self-directed learning, incidental learning, and socialization. Self-directed learning refers to learning through a project that individuals undertake either alone or within part of a group, with the intent of gaining new information or skills. Incidental learning experiences occur when the learner has not set out to learn something but learning occurs nevertheless. For example, a person is watching the news and learns about a new medication that could help control their pain from arthritis. Foley (2004) defines incidental learning as the learning that happens while people are performing other activities; for example, people who are repairing their cars will learn about the basics of auto mechanics. Marsick and Watkins (2001) describe incidental learning as a byproduct of some other activity. The third type of informal learning is socialization which is also referred to as tacit learning (Schugurensky, 2000). One of the examples Schugurensky uses is the learning that occurs when a child learns his or her first language. Language is learned therefore through socialization, by interacting with parents, care givers, and so forth.

Patient education experiences likely take place through the latter two categories of informal learning: incidental learning and socialization. While some patients may pursue self-directed informal learning, as in Merriam and Caffarella's (1999) example of a woman recently diagnosed with breast cancer who "decides to take an active role in planning her treatment" (p. 33), fatigue and other common physiological effects of many chronic diseases may limit use of this type of informal learning.

The objectives of patient education from the health system perspective include health promotion, disease prevention, risk factor modification, and disease management (Redman, 1997). Health promotion is usually geared towards the improvement of an entire population, or large segments of a population (Glanville, 2000). "The majority of targeted national health

objectives focus on changing health behaviour and advocate patient/consumer education as a key intervention strategy” (Donaldson, Rutledge, & Pravikoff, 1999, p. 1). Patient education directed at health promotion includes a general advertising and multimedia approach supported by the government. The goal could be to get the population to adopt an aspect of healthy living, such as eating a well balanced diet. For example, in Canada, Health Canada (1997) has produced the *Food Guide* which provides suggestions on which food groups are needed each day for a healthy diet.

Health education aimed at disease prevention is targeted to a specific demographic of the population which is at risk for a disease. Information about blood pressure monitoring, for example, could be categorized as a heart disease prevention strategy. Health education aimed at risk factor modification attempts to teach people to change lifestyle characteristics associated with the development of disease. There has been a concerted effort in Canada to get people to quit smoking to prevent further lung cancer and heart disease, two illnesses strongly associated with tobacco use (Health Canada, 1999a).

Finally, patient education targeting disease self-management aims to teach people with chronic diseases how to experience the best possible health in the presence of an incurable illness. Patient education on disease self-management has become increasingly important as chronic diseases have become a major cause of sickness and death in the world (Hohn, 1998). Due to the fact that participants in this study had experiences with this type of patient education intervention, this type of education will be discussed in more detail in the following section.

Patient Education Geared Towards Management of a Chronic Illness

Patient education and treatment is often geared towards a cure and return to previous health status for the patient who has a short term illness (Redman, 2004). With a chronic

illness, health may improve, but the individual is not expected to return to their previous level of health. In chronic conditions the patient's life is irreversibly changed. As well, neither the illness nor its consequences are static. Both interact to create illness patterns requiring continuous and complex management. Education to ensure that the individual becomes an effective "manager" of his or her health is therefore imperative.

For those who live with a chronic illness, patient education is usually focused on self-management, which is geared to reducing complications and optimizing quality of life (Lorig et al., 2002). Self-management refers to the decisions and actions taken by someone who is to manage their health problem and improve their health (Health Canada, 1999b). An important aspect of self-management is the ability to monitor specific disease symptoms. For example, someone with diabetes needs to be able to test for low blood sugar and take appropriate actions to reverse this condition. Other aims of chronic disease management education from health care providers include helping people adjust to social and workplace isolation and dislocation, cope with emotional reactions, and use medical and community resources to manage illness to optimize their quality of life (Wong, Gilbert, & Kilburn, 2004).

Health care professionals feel that patients need advice to understand and take control of their own health in the face of a chronic illness (Redman, 2004). Therefore patient education is usually geared towards behaviour modification. The focus of behaviour modification is either the adoption of a new behavior, such as exercising on a daily basis, or the discontinuation of an old behavior, such as smoking (Holman & Lorig, 2000). Weight loss, smoking cessation, and increasing activity levels are areas in which the health care provider attempts to provide the patient with knowledge and skills with the goal of altering behaviour. These patient education interventions therefore can be viewed as containing three

components: behavioural change, psycho-motor change (skills), and cognitive change (knowledge). Each of these components will be discussed in the following section.

Behaviour modification models. Within the area of behavioural change, researchers and practitioners have used models to try to understand/address the complexity of the surrounding issues for people with chronic illness. The three most well-known of the models reported are Self-efficacy (Bandura, 1982), the Health Belief Model (Rosenstock, Strecher, & Becker, 1988), and the Transtheoretical Model for Behaviour Change (Prochaska & DiClemente, 1985). All of these models have been used in patient education approaches to promote smoking cessation and weight loss (Hinchliff, 1999).

The Self-efficacy model is derived from Bandura's (1982) work on this concept with Social Learning Theory. Bandura postulated that individuals must have a sense of confidence or mastery in order to carry out a behavioral change. If individuals believe that they can carry out a behavior change, and they feel that this behavior change will lead to something they desire, they will undertake a task to change their behaviour (Lorig, 2001, p. 32).

Questionnaires have been developed to assess the self-efficacy of individuals with specific diseases who are involved in patient education. For example, the chronic obstructive pulmonary disease (COPD) self-efficacy questionnaire measures how confident a patient is in managing their breathing difficulties in different situations (Wigel, Creer, & Kotses, 1991).

The second model of behavior change, the Health Belief Model (HBM), developed by the United States Public Health service, tries to explain low rates of participation in disease prevention programs, such as the tuberculosis screening programs of the 1950's (Lorig, 2001). The HBM is widely used in the area of behavioral change and suggests that people will respond best to patient education on disease prevention when they perceive that

they are at serious risk for a disease. People will also best respond when they perceive that they will receive benefits from a suggested behavioral change and that the barriers to make that change are not great (Rosenstock et al., 1988). The implication of this model for the health care provider is that it is important to discover the patient's perception of his or her particular risk. As well, it is important for the health provider to remember that, even if patients perceive themselves at risk for a disease, they will still weigh the benefits of and barriers to the recommended behaviour change. Additionally, each behaviour change will be viewed and weighted differently by each patient. For example, a patient may be willing to take medication daily, but may be averse to dietary changes.

The third model of health behavior change, the Transtheoretical Model of Behaviour Change, posits that intentional behavioural change requires movement through specific motivational stages (Prochaska & DiClemente, 1985). This model is sometimes referred to as the stages of change model. The stages are pre-contemplation for considering change, contemplation, preparation for change, taking action to change, and maintenance of change.

In the pre-contemplation stage, the person has no immediate intention to change their behaviour. In the contemplation stage, the person has come to the realization that there is a problem and they are seriously thinking of changing their behaviour to address the problem. In the preparation for change stage, the person has taken some measures to begin the behavioural change, but has not yet taken effective action (Lorig, 2001). A person may take years to go through these first three stages, or may move quickly through the stages if they have had some major health crisis such as a heart attack. The stages of pre-contemplation, contemplation, and preparation for change can be thought of as stages of readiness. The action stage is when the person actually begins to change the behaviour. The final stage is maintenance. In this stage, the behaviour has become routine or a habit. One of the criticisms

of this model is that people will not necessarily progress through each stage one after another, but may go back and forth between stages (Redding, Rossi, Rossi, Velicer, & Prochaska, 2000).

With the possible exception of Self-efficacy, all three models fail to consider the impact of specific patient characteristics on the likelihood of behavioural change. Gender, culture, educational background, socio-economic status, personal beliefs and values, religious teachings, cognitive, psychomotor, language skills, and literacy are all believed to influence an adult's learning experiences (Walker, 1999). It would be reasonable to assume that these factors would all influence patient education experiences as well. Other factors such as insufficient social support, poor self-esteem, and distrust due to previous abuse of power by a health care professional, may also affect the patient education experience (Falvo, 2004).

Skills and Knowledge. In addition to behavior change, skill and knowledge acquisition, are other common goals of patient education. Most people living with chronic illnesses require skills to self-assess and self-treat the condition and its symptoms (Redman, 2004). For example, individuals living with diabetes must use a number of physical skills, as well as problem solving skills, on a daily basis. They need to be able to use physical skills to measure their blood glucose levels (self-assessment), problem solving skills and numeracy skills to determine how much insulin they need to inject, and finally, additional physical skills to inject the insulin (self-treatment).

Furthermore, it could be argued that all patient education attempts are to transfer knowledge from the health care provider to the patient. As well, the attempt to transfer knowledge is probably the most common component of all patient education.

It is important to note that many health professionals falsely assume that increased knowledge of a condition directly leads to behavior changes and improved self-efficacy. However, one study of a patient education program demonstrated that there may be other factors at work (Davis, Busch, Lowe, Taniguchi, & Djkwich, 1994). Davis and her colleagues evaluated the effectiveness of a patient education program for patients with rheumatoid arthritis using increases in knowledge and self-efficacy as outcomes. The educational program consisted of 33 hours of instruction over a two week period. The teaching methods used were group instruction, practical sessions, exercise classes, demonstrations, home study and individual treatment. Topics included energy conservation techniques, medications, joint protection techniques, diet and nutrition, and community resources.

Over a nine-month period, 56 participants were recruited from eight different programs in Edmonton, Alberta. A patient knowledge questionnaire about arthritis and an arthritis self-efficacy questionnaire were administered. The knowledge questionnaire had a test-retest reliability of .81 and internal consistency reliability of a Cronbach's $\alpha = .72$. The reliability of the arthritis self-efficacy questionnaire had an internal consistency reliability of a Cronbach's $\alpha = .90$ (Lorig, Chastain, Ung, Shoor, & Holman, 1989).

Davis and colleagues (1994) found that both knowledge and self-efficacy improved following the completion of the program. There were no correlations, however, between the changes in knowledge and self-efficacy from baseline to follow-up. The authors therefore concluded that this may indicate that the two variables improve independently of each other.

It is possible that increases in knowledge in any of the topic areas was not related to greater self-efficacy, but that other factors, such as the support of the other group members, influenced self-efficacy. Alternatively, it is possible that increases in only certain specific

areas of knowledge were related to changes in self-efficacy. The researchers did not ask the participants which topic areas concerned them most. Sub-analyses of the relationship between changes in knowledge in topic areas deemed important to patients and changes in self-efficacy would have allowed the researchers to test this hypothesis.

The question of whether imparting knowledge regarded by patients as highly relevant is important in inducing a behavior change is an extremely important practical issue. At present, there appears to be a significant disconnect between what patients want to learn and what health care providers think they need to know. For example, health care professionals continue to provide detailed information about anatomy and physiology in patient education sessions and pamphlets, when studies have shown that patients find information about treatment and prognosis more relevant and helpful to understanding their disease (Reid et al., 1995). Reid and colleagues investigated the text and reader characteristics that appeared to obstruct learning in diabetes management. Twenty-six adults with diabetes were asked to silently read a 1000 word excerpt from a common patient education pamphlet about diabetes that was given out in Missouri by health care professionals. The pamphlet excerpt dealt with the role of insulin, the two types of diabetes, and risk factors for the disease (Reid et al., 1995, p. 32). A prior knowledge true and false test about diabetes, that had been designed by a physician, was administered before the silent reading. After the participants read the excerpt, they were asked to state all the different ideas that they could remember from the pamphlet. The participants were prompted to continue until they could not recall any more information. The participants recalled on average eight of the 108 ideas units in the passage. The participants were also asked to indicate the 10 sentences that they felt were most important and these were compared to those sentences deemed most important by the

physician who had designed the prior knowledge test. Only “a third of the readers identified the same 10 sentences as the physician” (Reid et al., 1995, p. 36).

While the pamphlet had extensive information regarding patho-physiology, that is, how diabetes affects the body and how insulin works at a cellular level, the participants did not indicate that they felt these areas were important, although the physician did. Conversely, half of the participants felt the sentences dealing with outcomes, treatment, and symptoms of the disease were important; these sentences were not selected by the physician.

It should be noted that this study had a very small sample size, and included only one physician. The findings may therefore not be reflective of the degree of mismatch of vital information from both the patients and providers point of view. But the differences between what was seen as important by the patients and what was seen as important by the health provider may be a reflection of a relatively common problem.

Summary of the Literature Review of Patient Education

In this section, it was noted that patient education can serve a number of different purposes including health promotion, disease prevention, risk factor modification, and disease management. Due to the fact that this study focused on participants who were living with chronic illnesses, the literature related to chronic disease management, including the key area of behaviour modification, was included to help understand the patient education experiences that the participants may have had. Self-management is a major focus of patient education for individuals with chronic illnesses. To achieve self-management, patients are encouraged to make behavioural changes and develop the knowledge and skills important in self-assessing and self-treating. This can often involve nonformal and informal learning experiences for patients. These concepts will prove important in examining the patient education experience of individuals with limited literacy and chronic illnesses. The general

relationship between literacy and health will also be important. Literature relevant to this relationship will be explored next.

Literacy and Health

It is assumed that many readers will not be aware of the relatively recent field of study of literacy and health. The aim of this section is to introduce readers to the major areas of research and to demonstrate the need for the current study. The predominant focus in literacy and health research has been on developing assessment tools which have been used to establish prevalence rates of health literacy. Related tools have also been used to investigate health status and assess patient education material for reading level. To date, there is little literature on the experiences of individuals living with limited literacy and their health care experiences.

Assessment Tools

Many studies in the literacy and health field have focused on establishing tools to assess levels of health literacy. Presently, there are two assessment tools to measure health literacy: The Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1991) and the Test of Functional Health Literacy in Adults (TOFHLA) (Parker, Baker, Williams, & Nurss, 1995).

REALM. Davis and colleagues (Davis et al., 1991) developed the Rapid Estimate of Adult Literacy in Medicine (REALM) to assess the reading level of patients. Word recognition is the basis of the tool with the assumption that recognition of common medical terms is predictive of comprehension of those terms for the patient.

The REALM contains 66 medical words that are listed in three columns. A respondent is first asked to read the list aloud starting at the top left corner, which contains short, easier words (e.g., pill). The respondent then progresses down the columns to read

more difficult multi-syllabic words. If patients are unable to pronounce several words in a row, they are asked to look down the list and pronounce as many of the remaining words as they can. Dictionary pronunciation is the scoring standard utilized for the REALM. The REALM usually takes 2 to 4 minutes to complete (Davis et al., 1993). Raw scores are translated into a literacy grade range estimate. These grade ranges are grades 0 to 3, grades 4 to 6, grades 7 to 8, and finally, grade 9 and above.

The REALM's criterion validity was measured by its association with other word recognition tests. The REALM was found to correlate very highly with the Wide Range Achievement Test-Revised (WRAT-R), a general word recognition test that has been used in medical settings ($r = 0.88$) (Jastak & Wilkinson, 1993), the Slosson Oral Reading Test-Revised (SORT-R) (Slosson, 1990) ($r = 0.96$), and with the Peabody Individual Achievement Test-Revised (Markwardt, 1989) ($r = 0.97$) (Davis et al., 1993). The test-retest reliability of the REALM was estimated by the authors using a split-half reliability procedure in which Cronbach's alpha was 0.99 (Davis et al., 1993).

The REALM, as a word recognition test, does not measure reading comprehension or interpretation. Just because a person can say a word aloud does not mean that he/she understands the meaning of the word alone or in the context of health management. This is a major concern because both comprehension and interpretation skills are needed when using health information (Greenberg, 2001, p. 72). For example, one of the words on the REALM is "prescription." Even though participants can read the word prescription aloud does not mean that upon being given a written prescription, they understand that they require medication and that this paper should be taken to a pharmacist who will supply them with the medication.

TOFHLA. The TOFHLA was developed to address the noted concerns of the REALM, by assessing patients' functional health literacy. This test uses actual materials from a hospital setting, such as prescription medicine bottles, appointment slips, and informed consent forms (Parker et al., 1995). Functional health literacy is defined as “the ability of patients to complete successfully basic reading and numeracy tasks required to function adequately in the health care setting” (Williams et al., 1995, p. 1677). The test consists of two parts: (1) reading comprehension and (2) numeracy.

The reading comprehension section is a “50-item test using a modified Cloze procedure, where every fifth to seventh word in a passage is omitted and four possible options are provided” (Parker et al., 1995, p. 538). Passages are drawn from a standard informed consent document and the “Rights and Responsibilities” section of a Medicaid application. The numeracy section is a 17-item test using actual hospital forms and labeled prescription medicine bottles intended to test a person's ability to read and comprehend directions for taking medications, keeping medical appointments, monitoring blood glucose, and receiving financial aid.

The score obtained from the test results classifies a person's health literacy ability as one of three levels of functional health literacy. The levels are: (1) inadequate/low (a person is unable to read and interpret health texts), (2) marginal (a person has difficulty reading and interpreting health texts), and (3) adequate (a person can read and interpret most health texts) (Parker et al., 1995).

The TOFHLA's criterion validity was tested by examining the association between the TOFHLA, the REALM, and the WRAT-R. Correlations between the tests were relatively high with $r = 0.84$ and 0.74 respectively. Test-retest reliability was estimated at 0.98 using split-half reliability (Parker et al., 1995).

The TOFHLA takes approximately 10 to 20 minutes to administer. A shorter version of the test, known as the s-TOFHLA, takes approximately seven minutes to administer and includes 26 reading comprehension items and no numeracy items. Results of this shorter version have been shown to correlate highly with the full version TOFHLA ($r = 0.91$) and the REALM ($r = 0.81$). Test-retest reliability of the s-TOFHLA, as estimated by split-half reliability, was also high (0.97) (Baker, Williams, Parker, Gazmararian, & Nurss, 1999).

As with any assessment tool, and particularly with literacy assessments, the REALM and the TOFHLA must be administered with sensitivity and respect. As noted in a qualitative research study by Brez and Taylor (1997), “if perceived as tests, these interventions have the potential to cause learner anxiety which may negatively influence the results” (p. 1044). In addition, the benefits of using a tool need to be weighed against the possible decrease in self-esteem and self-confidence that screening may cause the patients (Brez & Taylor, 1997).

Both the REALM and different versions of the TOFHLA appear to have been used in only Canada and the United States and only for research purposes. The principal aim of these research studies has been to establish prevalence rates of health literacy in different populations which will be discussed in the following section.

Prevalence of Inadequate Functional Health Literacy

A large multi-centered study investigated the prevalence of low health literacy in two public hospitals located in Atlanta, Georgia and Torrance, California between November 1993 and April 1994. A total of 2,658 participants were interviewed for demographic information and assessed for health literacy level using either the English or Spanish version of the TOFHLA (Williams et al., 1995) while waiting for non-urgent care in the emergency department (Baker, Parker, Williams, Clark, & Nurss, 1997). Approximately 35% of English speaking and 42% of Spanish-speaking participants were classified as having inadequate

literacy. Marginal literacy levels were noted for 13% of English speaking participants and 20% of Spanish speaking participants. The researchers found that nearly 42% of participants were unable to comprehend directions to take medication on an empty stomach, 26% were unable to understand information identifying when their next appointment was scheduled, and just under 60% could not understand a standard consent form (Williams et al., 1995).

A similar study was conducted in four locations in the USA: Cleveland, Ohio; Houston, Texas; Southern Florida, and Tampa, Florida through the Prudential Health Care managed care organization (Gazmararian et al., 1999). The study was completed between June and December 1997 using a cross sectional survey design. The participants were 3,260 new Medicare enrollees aged 65 years or older. The participants completed a one hour in-person verbally administered survey in their homes. This survey consisted of “questions to determine demographic information, physical function, chronic conditions, health care use, mental health, cognitive impairment, social support and health behavior” (Gazmararian, Parker, & Baker, 1999, p. 546). The participants were assessed for health literacy level using the s-TOFHLA. Approximately 24% of the English-speaking and 34% of the Spanish-speaking participants were classified as having inadequate health literacy. Another 10% of the English-speaking and 20% of the Spanish-speaking patients were classified with marginal health literacy.

The results of these studies could be questioned on the basis of potential problems with the procedure used to measure health literacy and the psychometric properties of the TOFHLA. The TOFHLA endeavors to measure functional health literacy using reading comprehension and numeracy. The test, which uses material from everyday medical encounters, certainly has more face validity than the REALM. However, the use of the Cloze technique may be of concern. This technique may simply measure recognition of the correct

word for completing a sentence and not the actual comprehension of text. A person could pick the correct word but not be able to actually understand the sentence well enough to carry out the related activity. Therefore, the results of the TOFHLA could underestimate the extent of the literacy problems for a person. As well, similarly to the REALM, the tool's developers carried out all of the psychometric testing of the TOFHLA which introduces the possibility of bias.

However, the results of the ALL and the NAL in the United States, with large proportions of the population scoring in the lower ranges for general literacy, lend credence to the findings. Clearly, it is likely that low health literacy is prevalent in the United States. Given the similarity of literacy survey results between the United States and Canada, low health literacy is likely prevalent in this country as well.

Due to a paucity of literature in this area, the question remains: How closely is health literacy related to general literacy? It is possible that health literacy is a type of functional literacy that requires special skills or knowledge as does, for example, computer literacy? Despite limitations in our understanding of the differences and similarities between general literacy and health literacy, most research examining the relationship between literacy and health status has used measurements of health literacy. This research is presented below.

Health Literacy and Health Status

Researchers have found that inadequate health literacy is related to health status in a number of ways. People with inadequate health literacy are more likely to have overall poorer health status, limited use of preventive services, and increased hospitalization, in comparison with someone with adequate health literacy.

Using data from the same cohort of participants examined in the two public hospitals' study, participants' self-reported health and use of health services were investigated (Baker,

Parker, Williams, & Clark, 1998). This information was obtained during an interview in which demographic information such as age, years of schooling, receipt of food assistance, and having a phone were also asked. Participants were asked to rate their health as either poor or not poor. They were also asked whether they had visited a physician in the last three months and whether they had been hospitalized in the last year. Participants with inadequate functional health literacy were more likely to report health poor than were participants with adequate functional health literacy. Adequate functional literacy was more strongly associated with self-reported health than was number of years of school completed.

After adjusting for age, gender, race, self-reported health, socioeconomic status, and health insurance, “patients with inadequate literacy were 52% more likely to have been hospitalized than participants with adequate literacy” (Baker et al., 1998, p. 791). The authors suggested that inadequate literacy represents a significant barrier to understanding medical diagnoses and following treatment regimens, and therefore results in an increased risk of hospitalization. Visits to a doctor or hospital may not be the best indicator of overall health status. It is not known if the participants went to either their doctor or the hospital for a routine matter such as an annual checkup.

Baker and colleagues (2002) also reported on follow-up data from the original cohort from the four locations. The participants' hospital admissions from 1997 to 1999 were tracked using health care claim forms kept by the managed care organization. Findings indicated that participants with inadequate health literacy were 43% more likely to have been hospitalized compared to the ones with adequate health literacy.

These same participants were asked about their knowledge and use of preventive health services. Both men and women were asked: (1) if they had a flu vaccination and (2) a pneumonia vaccination. Women were given a brief definition and asked if they ever had: (1)

a mammogram and (2) a Pap smear (p. 400). After adjusting for years of school completed, income, number of physician visits and health status, statistically significant differences in preventive behaviors remained between the participants with inadequate versus adequate health literacy (Scott, Gazmararian, Williams, & Baker, 2002). Participants with inadequate health literacy were less likely to report getting a vaccination for influenza or pneumonia and women participants were less likely to have received a mammogram or Pap smear in the last year.

A potential criticism of this study is that participants could have used a preventive service but the participants may not have known what the word vaccination or Pap smear meant and therefore answered that they hadn't had the procedure. This lack of word recognition may have been more common among individuals with inadequate health literacy. This may have resulted in an overestimation of the number of people who actually didn't have a Pap smear or flu vaccination.

Another concern for all of the above studies is that the data only came from two groups of participants. Therefore, methodological problems, such as potential problems with the Spanish version of the TOFHLA in the first study, would be reflected in the subsequent analyses that focused on a specific aspect of the study. As well, since the results are based on data that was collected from seven to ten years ago, they may not reflect the current state of affairs.

In a completely different study, Bennett and colleagues (1998) evaluated the association between poor literacy skills and the frequency with which patients presented with advanced stages of prostate cancer among low-income black and white men who received care in equal-access Medicaid insurance covered Veteran Affairs Hospitals and University Hospitals. The participants were 212 consecutive English-speaking men awaiting their

appointment in two prostate cancer clinics. The men were assessed for health literacy using the REALM and their charts were reviewed for demographic information, age, and pathologic stage of their prostate cancer at the time they were diagnosed. Cancer tumors are generally categorized into standard stages according to how severe the cancer is and whether or not the cancer has spread or metastasized to other areas of the body. The stages of prostate cancer range from early disease in Stage A to advanced, metastatic cancer in Stage D (Bennett et al., 1998). The findings indicated that 49.5% of black men and 35.9% of white men had Stage D cancer when they were first diagnosed. Their REALM literacy scores were less than Grade 6 literacy level for 52.3% of black men and 8.7% of white men. Men with less than Grade 6 literacy levels were more likely to have advanced-stage prostate cancer at diagnosis. The authors used logistic regression analysis to adjust for differences in literacy, age, city, and race. Low health literacy remained the only significant predictor of advanced-stage prostate cancer at diagnosis. The researchers concluded that low health literacy is an overlooked barrier to early diagnosis.

A limitation of this study is that it is possible that the men who presented with a more advanced stage of prostate cancer may not have been aware of the availability of screening services. They might also have thought that these preventive services would cost money. However, both possible explanations may be related to literacy.

Health Literacy and Patient Education

Researchers have also investigated the relationship between health literacy of patients and the estimated literacy levels required to understand patient education material provided to these patients. Significant gaps have been found between the readability of patient education material and the health literacy levels of patients. Heath-Holmes and colleagues (1997) investigated the readability of patient education materials for patients with Systemic

Lupus Erythematosus (SLE), a chronic rheumatic disease that can affect many different parts of the body, including the muscles, heart, and lungs. Ninety four participants who were diagnosed with SLE were recruited from either a university clinic or a private clinic in Shreveport, Louisiana. The participants were administered the REALM and asked demographic information including age, educational attainment level, household annual income, and present or last occupation if the participant was unemployed. The researchers selected 18 different SLE-related patient education printed materials used in these settings. The patient education material was tested for reading level using the computer program Grammatik. This program analyzes text by looking at the number of words in a sentence, the average sentence length, and the number of syllables in a word. The researchers found that 48% of the participants had less than a grade 9 level of health literacy according to the REALM, while only 11% of the patient education material was written below a grade 9 level. In fact, they found that the majority of patient education material was written at or above a grade 11 level, while the average reading level of the participants was a grade 7 to 8 level.

There are many concerns with readability formulas. These formulas work from the assumption that shorter words, and shorter sentences, are easy to understand. This may not always be the case. Of greater importance may be how these words are used, and in what context. For example, the word run is a very short word which can be read with a grade 1 level ability. However, the word run when used in the context of computer usage, means to start a software program which entails either hitting the enter key on the keyboard or clicking an icon on the screen. When the word is used in the context of mobility, such as to go for a run, it has a very different meaning. Determining which meaning is intended requires more than simple word recognition.

The association between health literacy and the understanding of specific disease symptoms has been investigated using knowledge questionnaires. Researchers have found that people with low functional health literacy are less likely to know the specific symptoms of their disease. Kalichman and colleagues (2000) studied the relationship between health literacy as measured by the TOFHLA and knowledge and understanding of HIV/AIDS. English speaking individuals included 228 men, 65 women, and one transgender person who were recruited through AIDS service organizations and HIV clinics. The study design was a cross sectional survey. The data sources were demographic information, the TOFHLA results, and results of a knowledge test designed by the researchers to measure comprehension of HIV related concepts, such as Cluster of Differentiation 4 (CD4) count and HIV viral load. Both of these are laboratory values that are used to monitor the progression of HIV infection. The participants were also asked questions concerning their perception of anti-HIV treatment. Eighteen percent of the participants scored 80% or lower on the reading comprehension portion of the TOFHLA, which the authors interpolated as low health literacy. The researchers found that after controlling for years of education, persons of lower health literacy were significantly less likely to state that their doctor asked their opinions about their treatment and were somewhat less likely to know their CD4 cell count and viral load. As well, participants with lower health literacy who knew their CD4 count and viral load were less likely to understand the meaning of these measures. Lower health literacy was also related to misperceptions that anti-HIV treatments reduce the risk of sexually transmitting HIV, and thus that safer-sex practices were no longer required.

The authors chose to use quite a high cut off rate to categorize participants as having low health literacy. This may have resulted in over-estimating the proportion of participants with inadequate health literacy. Also, knowledge of CD4 count and viral load is only one

aspect of knowledge of the disease. Nevertheless, the finding that there is an association between lower health literacy and misconceptions about disease transmission has implications for patient education specifically and public health in general.

In another study of health literacy and health knowledge, Williams, Baker, Honig, Lee and Nowlan (1998) found that 92% of patients with hypertension and adequate literacy levels according to the TOFHLA, knew that a blood pressure reading of 160/100 mmHg indicated high blood pressure, while only 55% of those with inadequate literacy level had this knowledge. Williams and colleagues (1998) also carried out a study on the relationship between health literacy and asthma knowledge and the ability to use a metered-dose inhaler (MDI) (a common medication delivery device use by people with asthma). The investigators interviewed 483 patients with asthma and assessed their health literacy using the REALM. The participants were also verbally tested for knowledge of asthma and asked to demonstrate the use of a MDI. The data revealed that participants with lower REALM results scored lower on both the asthma knowledge test and demonstration of the MDI. The authors concluded that adults with low literacy skills and asthma also had poor self-management skills. However, it is noted that there may not be a direct correlation between the ability to physically demonstrate a skill and the ability to carry out the problem solving required to use that skill at the appropriate time, which is the case for asthma.

Living with Limited Literacy and a Health Problem

There are few studies that look at issues of literacy and health from the perspective of people living with limited literacy. Parikh, Parker, Nurss, Baker and Williams (1996) studied the relationship between shame and low functional literacy in health care settings. Their sample of 202 participants included 102 women and 100 men who were awaiting non-urgent care in the emergency room or a walk-in clinic in a large urban hospital. They ranged in age

from 18 to 88 years with an average age of 41.4 years. The authors interviewed and assessed these English-speaking participants using the TOFHLA. Possible participants were asked at the beginning of the interview if they had difficulty reading. If they answered no, the interview was stopped and they were excluded from the study. If they answered yes, they were asked four questions designed by the researchers. The questions started with hypothetical questions about people in general with reading difficulties and then progressed to personal questions about the participant's own reading ability. The researchers used a five-point Likert scale to score the questions.

The authors combined the inadequate and marginal functional health literacy categories of the TOFHLA in their reporting of their results and labeled this combined group as having low health literacy. They found that 42.6% of participants had low health literacy and, of this group, 67.4% admitted they had problems reading. For those who admitted they had reading problems, 39.7% admitted associated feelings of shame. Also, 67.2 % of participants who admitted to having reading problems had not shared this knowledge with their spouse.

Due to the fact that people had to self-report reading problems, these findings may have actually underrepresented this issue because a number of potential participants with reading problems may have denied them on the first question and were thus excluded from the study. As well, although the information gained was valuable, these researchers only asked participants four close-ended quantitative questions. It is likely that many of the issues surrounding limited literacy and shame were not uncovered or explored in detail.

From other studies, the shame associated with limited literacy appears to be related to a social stigma surrounding literacy. As well, social conditioning has developed over the years as people have tried to hide their literacy problems (Beder, 1991). This theme of stigma

that is linked to limited literacy has emerged from a qualitative study examining adults' responses to being screened for reading ability using the REALM (Brez & Taylor, 1997). The purpose of the study was "to gain understanding of the response of English-speaking adults with low literacy skills to screening of reading ability to facilitate the planning of patient teaching in a hospital setting" (Brez & Taylor, 1997, p. 1040). The eight participants included four women and four men; their ages ranged from 21 to 55 years old with an average age of 35.6 years. These participants were recruited through a local community literacy program and had had a recent experience as a patient in a hospital.

A multiple case study approach was used and included the REALM and semi-structured interviews. Five themes which emerged from the data were:

1. Risk of exposure: the stigma of illiteracy
2. Risks of non-disclosure during hospitalization
3. Understanding the hospital as a "special" place
4. Support for the concept of screening
5. Experiential factors influencing response to literacy assessment

Brez and Taylor (1997) noted that participants did not want people to find out about their literacy difficulties because they felt that "exposure would result in decreased self-esteem, and social acceptance" (p. 1043). Participants "expressed fear that their role as a competent adult, parent or family provider would be questioned and challenged if their illiteracy was known" (Brez & Taylor, 1997, p. 1043).

In an American qualitative study, Baker and colleagues (1996) explored the health care experiences of people with low health literacy. They recruited participants from two large urban public hospitals emergency departments. English speaking participants who had been rated as having low and marginal health literacy according to the REALM, and Spanish-speaking participants who could not read any of the Spanish words translated from the REALM, were asked to return for the interview phase of the study. In total, 60

participants were interviewed, 11 participants were individually interviewed, and 49 participants attended focus groups; 10 of these participants were Spanish speaking and attended a Spanish speaking focus group.

Six themes emerged from the interviews and focus groups. The themes related to barriers that participants faced in the health care setting. These barriers were: navigation (finding the hospital and locating departments), completion of forms, following medications instructions, provider-patient interactions, and coping strategies. Perhaps of greater concern was the finding that patients reported that they did not seek medical help because of being embarrassed by their literacy problems (Baker et al., 1996).

In addition to Brez and Taylor (1997), two other Canadian studies have examined issues surrounding living with limited literacy and interacting with the health care system. One was in a rural setting and the other was in an urban setting. The purpose of Gillis and Quigley's (2004) project partnership, with health care, social services, and literacy groups, was to study the "factors that influence the ways less literate adults living in northeastern Nova Scotia access and act upon health information and services, and what strategies for change will build upon existing capacities for achieving health?" (p. 4).

The final report from the project was entitled "*Taking off the blindfold: Health Literacy in Rural Nova Scotia Research Project: Exploring the links between literacy and health.*" One of the participants said

you ought to be able to learn how to read and write in this world or you are done for See, we are kind of like blindfolded ... yeah, just like you are in the dark. A lot of people, you know, can't read (Gillis & Quigley, 2004, p. 1).

Using an ethnographic methodology, data collection occurred concurrently with three different groups: interviews with adults whose lives had been affected by limited literacy,

individual interviews with key informants, and group interviews with health and literacy practitioners. Working with members of the advisory committee and local service providers including local literacy organizations, 46 adults whose lives had been affected by limited literacy were identified and interviewed. Of those interviewed, 25 were enrolled in adult learning programs and 21 were recruited through a hospital-based diabetes out-patient clinic or community-based health agencies such as an addiction treatment service, a community health centre, and a women's resource centre. They included 15 males and 31 females ranging in age from 18 to over 55 years who had completed between first and twelfth grade. Participants included four Acadians, five Mi'kmaq, and four African Nova Scotians (Gillis & Quigley, 2004).

Twenty community leaders who worked in either health or literacy organizations were also interviewed individually as additional key informants. As well, seven group interviews were held with 64 health and literacy professionals whose practice involved working with adults limited in literacy. In total, 130 people were interviewed for this study.

The in-depth interviews used a reflective adult learning process. The first step was to ask the participant to talk about past experiences in the areas of literacy and health. The second step was to have the participant reflect upon the meaning of these experiences, the underlying causes, and how the experience fits into a larger picture. The final step was to ask the participants to suggest action for what needed to happen on a personal, community, or policy level to make the situation better. The interviews were transcribed and themes were derived by the research team and presented to the advisory committee for discussion and feedback.

The four themes that emerged from the data were: (1) social isolation; (2) lack of transportation; (3) limited opportunities and/or decreased access to employment, recreation,

health care, education, and social support services; and (4) accessibility of affordable health care resources. Social isolation included the recognition from participants that although there was support in smaller communities, they still felt isolated due to their physical removal from larger communities. The lack of transportation theme included the lack of public transportation in rural communities. Some participants felt that the inability to leave the small community could result in a lack of knowledge as well. They would not be aware of what could be offered to them in terms of health services because they could not access these services unless they were able to travel to the larger communities. Again, the theme of limited opportunities and/or decreased access to employment, recreation, health care, education, and social support services highlights the differences in living in a larger community versus a smaller isolated rural environment. The participants also acknowledged that there was a lack of accessibility to affordable health care resources due to living in isolated rural communities. Participants had to actually pay more for health care products and services, such as insulin, in their community, than in larger communities.

Participants made numerous suggestions. The suggestions included finding ways to reduce barriers to enrolling and attending literacy programs in rural areas as well as increasing awareness of literacy issues among services providers. Because the intent of this research was to provide a basis for improving public policy and programs to enhance the capacity for health of less literate adults living in rural northeastern Nova Scotia, many of the suggestions were geared towards an improvement in policy and service delivery. Other suggested service delivery changes included supporting the use of client advocates to help people move through the health care system, and taking health information and services to the people in rural areas. One such example was the use of mobile health units (Gillis & Quigley, 2004). There were a number of limitations in this study. First, the researchers chose

not to do any literacy testing of the participants. While lower literacy can be inferred for those individuals recruited from literacy programs, actual literacy levels of the participants are unknown. Second, although some of the participants were recruited through hospital and community-based health programs, the specific health issues or conditions that the participants had were not recorded. Third, many of the themes that emerged may have been related more to issues surrounding obtaining health care in a rural community, as opposed to interacting with the health system when one has lower literacy.

The second recent Canadian study was a large multi-phased project conducted in Quebec (Centre for Literacy of Quebec, 2001). The research began as a result of professional development workshops about literacy and health that had been conducted by the Centre of Literacy for Quebec during the mid to late 1990's in hospitals in Montreal. Following the merger of five large teaching hospitals to form the Montreal University Health Centre (MUHC) in 1997, health care providers expressed a need to address issues related to literacy and health across this new organization. A Health Literacy Committee was established to address these issues. The project had three phases: Phase I, a needs assessment conducted in 1999-2000; Phase 2, an implementation of recommendations and strategies from the first phase conducted in 2001-2002, and Phase 3, an extensive review of the medical and education literature on alternative methods of health communication and the development of a conceptual framework which is on-going. An additional component, Phase 4, to change practice and policy and enhance health communication strategies with marginalized populations, has not started.

The overall purpose of Phase 1 of the project was to determine the health information and health education needs of "hard-to-reach" patients at the MUHC. During Phase 1, the term "hard-to reach" was used by the MUHC staff to describe patients identified by nurses as

facing literacy, language, and cultural barriers, and those who have difficulties processing health information because of physical or cognitive disabilities. Using a qualitative research methodology, data were collected through individual and group interviews. Sixty-six health care workers, including employees from two affiliated community health clinics, were interviewed individually. Forty-five additional individuals were interviewed in seven focus groups. These included people from four groups of informants: hard-to-reach patients, members of their families, support staff, and health care professionals who were working in one of three outpatient units: the Dialysis Unit, the Oncology/Hematology clinic, and the Pre-operative clinic. Attempts were made to include an equal proportion of participants who spoke primarily English, French, or another language, and to balance gender, age, and socioeconomic backgrounds (Centre for Literacy of Quebec, 2001).

One of the key findings from Phase 1 suggested that health care professionals gave less information to patients they identified as “hard-to-reach” because they did not want to overload the patients. They identified these patients by cues that they noticed in their interactions with them. These cues included a patient who would not read in front of someone, or who would say they understood everything. As well as the cues, health care professionals would describe someone “hard-to-reach” as someone who was “disadvantaged or poor patients, older patients, patient who smoke and have bad health habits and patients who live in poor neighbourhoods” (Centre for Literacy of Quebec, 2001, p. 74). It appeared that some health care professionals made assumptions on how much or what type of information they would give an individual patient based on these cues and life factors without actually engaging the patient in a discussion on their information needs.

Another key finding was that “a majority of the patients found written documents not directly useful” (Centre for Literacy of Quebec, 2001, p. 19). Reasons that the patients gave

included they did not read English or French, they did not like to read, and that their caregivers took responsibility for reading. Other significant findings were that “patients and professionals have different perceptions of the health education needs of this group and that their family members want different information than patients” (p. 18).

In Phase 2, selected recommendations from the first phase were tested with patients. These recommendations included using multiple delivery approaches for health information to access the effectiveness of these different approaches. Health information was created using multiple approaches, including those that had graphic cues and/or translated text. For example, for the Oncology/Hematology unit, a storyboard poster format was produced which outlined in picture form the 10 steps involved in a patient’s first day of chemotherapy (Centre for Literacy of Quebec, 2002). This storyboard poster only used pictures without any text. There was no formal evaluation of these modified materials but informal feedback was gathered from patients and their families.

Key findings from Phase 2 indicated that patients’ responses to these materials were influenced by many factors, not only the use of text and images. These factors include such things as complicated cognitive problems, and linguistic and cultural barriers (Centre for Literacy of Quebec, 2001, p. 9). Therefore, the researchers concluded that there is a need to customize communication according to identified barriers/needs for the individual patients. There also needed to be a clearer understanding of who comprised the “hard-to-reach” patient groups before appropriate means of communication for such groups could be developed. As well, the researchers identified the need for a conceptual framework to guide initiatives related to health communication and education materials.

Given the findings from Phase 2, Phase 3 included a review of the medical and education literature on alternative methods of health communication. The review included

the use of plain language in patient education material and the use of different patient education delivery methods such as audiotapes, videotapes, interactive media, and graphic images. The key finding to date indicates that “most evaluative studies on plain language and audiotapes excluded those who did not speak English, were unable to read or had other physical or cognitive deficits, i.e. the marginalized groups” (Atkinson, 2003, p. 1; Santo, Laizner, & Shohet, 2004).

The researchers concluded that health communication is a shared responsibility between patients and professionals and that there was no easy short-term fix. They recognized that a long-term view is needed to establish the case for literacy and health as a key component of health communication. This long term plan needs to take into consideration “varied interests in health care sector, including taking the time to build understanding and support among front-line providers and time to sell the concept to leadership and policy-makers” (Centre for Literacy of Quebec, 2001, p. 5).

The participants in the Montreal study were not assessed for literacy ability. “Hard to reach” patients included a broad range of individuals that had been identified by health care providers. Therefore, it is possible that at least some participants did not have literacy problems and that there would have been other participants who had cognitive limitations, due to their health problems, that may have affected their understanding of health information. Their experiences might be very different from those with limited literacy. While these studies have delved more deeply into the experiences of individuals with low literacy in the health care system, none have investigated patient education experiences.

Summary of Literature Review of Literacy and Health

Within this section, the literacy and health literature in key areas has been introduced, reviewed and critiqued. The two major assessment tools, the REALM and TOFHLA, were

presented. These measurement tools were discussed to provide a basis to explore the other studies in the area of literacy and health and to highlight how these tools have been used in health services research. The research studies which have investigated the correlations between literacy and health, health status and patient education were presented. Finally, the previous research that has focused on the health experiences for people living with limited literacy was presented to shed light on living with limited literacy and a health problem.

Summary of the Literature Review

In summary, despite methodological issues noted above, a number of conclusions regarding health and literacy are plausible. First, it appears that literacy is a complex phenomenon, which, although not completely understood, affects all aspects of people's lives including their health status. There also appears to be a relationship between low functional health literacy and decreased health status, as reflected by increased hospitalizations and reduced use of preventive health services. It also appears that people with low functional health literacy are more likely to misinterpret medication instructions and less likely to seek medical attention.

From the patient education literature, it was found that educational materials and interventions for patients with chronic illnesses are geared towards transmitting knowledge and teaching the skills both of identification of disease symptoms and of self-management. Investigators have determined that people with low functional health literacy are more likely to have insufficient knowledge of their disease symptoms. Also noted is that a significant gap exists between the readability of patient education material and the literacy levels of patients with chronic illnesses.

From the qualitative studies examining adults' experiences living with low literacy skills, themes of stigma and shame are consistent. Findings confirm a tendency of individuals

with low literacy to avoid seeking medical services and identify other barriers to health services.

Qualitative research has not yet been used to explore the patient education experiences of individuals with low literacy. Qualitative inquiry, however, has the potential to yield rich information that could illuminate this undocumented experience for the benefit of health care recipients and providers. This study will attempt to address this gap in the literature using the concepts of literacy and health.

Adult Learning Theories

There are a number of theories in adult education that endeavor to clarify the complex process by which adults learn through experience. This perplexing process involves the interaction of the learner, the instructor, the learning process, the learning context, and the learning outcome. Each adult learning theory chosen for this study places a different emphasis on each of these elements. The different theories discussed here attempt to provide a deeper understanding of how cognition processes, experience, construction of knowledge, transfer of knowledge, and social action are all connected to adult learning. The theories' foundations and key concepts are drawn from a variety of fields such as behavioral science, psychology, sociology, and education. Many of the proponents of these theories argue that the theories are still evolving. This results in changes to concepts and even changes to the theoretical foundation as new research findings emerge and the fascinating and multifaceted picture of how adults learn becomes clearer.

Each of these adult learning theories focus is on one of these three elements: individual, context, and system that are felt to be part of the patient education experiences. Transformational learning theory may be useful to examine the participants' individual experiences, taking into consideration that a major goal of patient education is to transform a

person's behaviour. The idea of situated cognition may be useful in understanding the patient education experiences of individuals with limited literacy in the health care context. Finally critical theory was chosen to look at the role the system, including any barriers that were put in place by the system, had in the participants' patient education experiences. A brief review of the theoretical foundation and key concepts of each theory will be presented at this point to introduce the reader to these theories. A critique of each theory is also provided to demonstrate how the theories complement each other which may be helpful to provide a structure to describe the different components of the learning experiences for the participants.

Transformational Learning Theory

Transformational learning theory provides a basis for understanding how adults interpret and make sense of their experiences and act in their worlds. The theory attempts to explain how adults use critical reflection in learning. The key concepts of transformational learning theory are meaning schemes, meaning perspectives, and critical reflection.

Meaning schemes are specific beliefs, judgments, feelings, and attitudes which to some extent can be viewed through behaviour and verbal interactions (Mezirow, 1996). Meaning schemes are based upon experiences and are acted upon in a rational way (Taylor, 1998). Meaning perspectives are broad, generalized predispositions or lenses that filter perceptions and comprehension of new experiences (Cranton, 1998). Adults with limited literacy will have meaning schemes and perspectives about illness. How these meaning schemes and perspectives are altered when they personally have to deal with a chronic illness is not known.

Mezirow (1991) has insisted that the capacity to reflect critically on taken-for-granted assumptions is the major difference between learning in childhood and adulthood.

Critical reflection involves examining the content of a problem, looking at the process of problem solving, and most importantly, questioning the premise underlying the problem. Critical reflection begins with a disorienting dilemma or crisis event when, for instance, an individual is diagnosed with a chronic illness. The individual tries to make sense of this event using his or her 'normal' ways of thinking and then realizes that these ways do not work. A feeling of discontent develops, which leads to an examination of meaning schemes through the process of critical reflection. Then, there is recognition that this discontent and the process of transformation are shared, and that others have been able to make a similar change. This is followed by an exploration of new ways of being which involves changing meaning perspectives, acquiring new knowledge and skills, and then a building of competence in new roles or ways of being (action) and reintegration back into his or her life (Mezirow, 1991). Critical reflection for Brookfield (1991) involves the identification of a problem or incident that represents some aspects of practice requiring examination and possible change. Brookfield (1995) believes that by identifying the assumptions that underlie our beliefs and actions connected to this problem, we can better analyze the nature of our practice. This process results in the capacity to imagine and explore alternatives to existing ways of thinking.

The concept of transformational learning has been used in studies investigating patient education experiences for patients with chronic illnesses. Recently, Ashe, Taylor and Dubouloz (2005) conducted a study to explore clients' experiences in two different arthritis education groups to develop an understanding of meaningful group experiences in the process of change leading to desired health outcomes. A phenomenological approach and transformational learning theory was used when analyzing the data. Ten participants who had rheumatoid or inflammatory arthritis were interviewed individually and in focus groups.

Three themes emerged: The first was validation through connection, which involved the participants' experiences with health care professionals and others and the participants' "discomfort with arthritis as a chronic disease" (Ashe, et al., 2005, p. 284). The second theme was restructuring illness identity that emerged from the participants' "restructuring beliefs about self and disease, helping others and comparing to others" (Ashe et al., 2005, p. 285). The final theme, perceptions of self and disease symptoms, included participants' thoughts on living with pain, feelings of power through disease knowledge, and reflections for action and inaction. The authors concluded that the clients had changed their meaning perspectives about their chronic illness due to their participation in health education groups. This process of change in meaning perspectives could lead to changes in health behaviors and desired health outcomes. These health outcomes were desired not only by the patients, but were seen as important indicators of chronic illness management by the health care provider.

According to transformational learning theory, critical reflection requires rational and logical thought. Additionally, rational thought is seen as something that the learner can always separate from the learning experience, which may not be the case when individuals are dealing with emotional issues such as health and illness.

A major concern about this theory is that it does not take into account the power of the social learning context, which may block this emancipatory learning from taking place. Yet Mezirow (1995) believes that "transformation theory is an expression of democratic culture: it demands that we become aware of how we come to our knowledge and about the values that lead us to our meaning perspectives" (p. 70). Mezirow (1991) also believes that taking action is integral to transformative learning and this action usually involves an empowered sense of self, a critical understanding of how one's social relations and culture

have shaped one's beliefs and feelings, and strategies for taking action. Transformational learning theory can be seen as emphasizing personal development, which may lead to social change later on. However, this emphasis on personal development may not be enough. Newman (1994) argues that transformational learning theory appears to require the oppressed to liberate themselves without disempowering the oppressors.

Clearly, transformative learning emphasizes the individual learner, but does not take into consideration how the learning context or situation affects the learning process. However, the learning context is key to situated cognition theory.

Situated Cognition Theory

According to situated cognition theory, learning is a complex interactive and collaborative social phenomenon. Within situated cognition theory, the learner, the learning process, and situation in which the learning is presented are intertwined and cannot be separated.

Vygotsky's (1978) sociocultural approach to learning and cognitive learning (see Merriam & Caffarella, 1999), concepts of perception, insight, and meaning that are within the learner's control, influence situated cognition theory. The theory questions the assumption that all learning is an internal process. It tries to explain cognition, including problem solving, sense making, understanding transfer of learning, and creativity, in terms of the relationship between learners and the properties of specific environments (Barab & Duffy, 2000). Meaning making is therefore both a mental and social interchange, with learning and cognition being fundamentally situated (Brown, Collins, & Duguid, 1989). In situated cognition theory, reflection and experience are important to learning, but in contrast to transformational learning theory, "learners no longer learn from experience, they learn in it" (Wilson, 1993, p. 75). Situated cognition theory's key concepts are: situated learning,

anchored instruction, and cognitive apprenticeships (Merriam & Caffarella, 1999, p. 240-247).

Situated learning can be seen as the practical component of the situated cognition theory. The four elements of situated learning are content, context, community, and participation (Stein, 1998). Content includes the facts and processes of the task, such as the curriculum of patient education programs. Context includes the situations, values, beliefs, and environmental cues of the learning activity. In the health care context, the patient rarely has any control over when and where patient education interactions occur because the health care professional usually dictates these parameters. Community is the group of people with whom the learner negotiates and creates meaning. Through community, learners interpret, reflect upon, and form meaning. Participation is the process whereby learners work with instructors and peers to solve problems related to daily living (Kirshner & Whitson, 1997) and includes the interchange of ideas and requires dialogue with members of the learning community. Anchored instruction refers to instruction in which the material to be learned is presented in the context of an authentic event that serves to anchor or situate the material and further allows it to be examined from multiple perspectives (Barab & Duffy, 2000).

The emphasis on the authentic event or context is where this theory differs from some other adult learning theories. The theory posits that a learner requires a learning context that is closer to real world experience. Within a patient education context, this could involve health care professionals teaching patients how to perform a physical skill in their homes, such as climbing stairs after an injury.

Modeling, mentoring, coaching, scaffolding, and experiential learning are all aspects of cognitive apprenticeships (Wenger, 1998). The cognitive apprenticeships must involve pertinent situations or tasks that the learner would encounter in the real world. These

situations have been labeled learning-in-practice (Lave & Wenger, 1991), and communities of practice (Lave, 1997). The learner must “learn not just what and how to perform, but also what the performance means in order to function and be accepted as a full member in the community of practice” (Lemke, 1997, p. 43). A community of practice is the culturally organized setting that embodies the beliefs and behaviors to be acquired by the learner (Lave, 1997). According to Wenger (1998), communities of practice are self-organized or selected groups of people who share a common sense of purpose and a desire to learn and know what others know. According to Lave and Wenger (1991), as beginners move from the periphery of this community to its center, they become more active and engaged within the culture and hence assume the role of expert or old-timer. This movement rests on the ability of instructors to alter their role from one of knowledge transmitter, to coach, or facilitator.

Situated cognition theory implicitly proposes that the situational nature of acquiring knowledge is the key to understanding cognition and that cooperation will occur in all communities of practice regardless of possible learning ability differences among learners. This may not be the case for every learner (Anderson, Reder, & Simon, 1996). With this complete emphasis on situational learning, it is difficult for the theory to explain how a learner can learn in an abstract context and transfer this knowledge into practice. Cognitive apprenticeships are seen as a way for learners to generalize “what they have learned as both a way to apply this learning to similar situations and as a starting point for further learning” (Merriam & Caffarella, 1999, p. 245). The theory also puts a lot of importance on cooperation within the community of practice, particularly between the newcomers and the old-timers. The theory does not take into consideration what the learner needs to do if cooperation does not occur.

Although the learning situation is crucial to the theory, issues of knowledge and power within situations are not taken into consideration. Kirshner and Whitson (1997) question whether in situated cognition, the issues of knowledge and power are not seen as a legitimate part of the study of cognition. This is not the case for critical theory, which focuses on the issues of knowledge and power.

Critical Theory

Critical theory acknowledges the importance of the learning context or sociocultural aspect to acquiring knowledge. In critical theory, societal power informs the learning context and process. Failure to learn can be understood as a systemic social problem, rather than one of individual failure. Critical theory does not just attempt to explain adult learning; it is a larger, almost a grand theory of the world. It challenges the status quo and has the goal of liberating individuals from oppression and freeing the human spirit. It has been used in education, qualitative research, religion, political science, and economics.

Critical theory traces its roots to Marxism and was later expanded by Habermas (1971) who believed that there was a relationship between power and knowledge. The theory's use in adult learning was pioneered by Freire (1970) and elaborated by Giroux (1983). Freire's work with adults in literacy programs in Brazil was the basis of his work on critical pedagogy. For Freire, critical pedagogy is concerned with the development of *conscientização*, a critical consciousness. Freedom, for Freire, begins with the recognition of a system of oppressive relations, and one's own place in that system (Popkewitz & Fendler, 1999, p. 51). Freire's theories have had far reaching influences on adult education practice throughout the world.

Giroux's theories lie in the area of empowerment. For Giroux, education and educational institutions empower the already empowered in society and are maintained to

disempower the marginalized in society. He feels that schools should be the sites of transformation of culture, not just reproduction of the empowered domain elite's culture. In his view, this transformation can only occur through radical pedagogy.

In critical theory, the learner must overcome power-related obstacles to achieve full learning potential and active participation in society. Learner characteristics such as limited literacy are assumed to be a systemic social problem and not an individual problem.

The key concepts of critical theory are reflective discourse, institutions as learning communities, and the interplay of the life-world and the system (Welton, 1993). In critical theory, individuals take meaning from an experience as opposed to giving meaning to an experience in transformational learning theory, and learning within an experience in situated cognition theory. The meaning taken from experience is socially constructed and will affect how, what, and when a person learns. Critical theorists believe that human beings have the capacity to be reflective in learning, but that the conditions of life, social context, and culture can block or distort learning (Welton, 1995b). In critical theory, reflection becomes a form of inquiry used to understand the relationship between power and knowledge in the learning experience (Garrick, 1996). The focus of reflection has moved from the learner in transformational theory, to the situation in situated cognition and finally, to the system in critical theory. According to Habermas (1971) all institutions are educative, but not all are true learning communities. An institution may be organized to actually block free and noncoercive learning processes. Habermas (1971) encourages us to ask whether "our institutions, large and small, truly enable human beings to unfold their potentials (cognitive, oral, technical, aesthetic) in their daily routine interactions" (p. 89). The social and historical context of these institutions needs to be acknowledged as having influence on the learner (Welton, 2005).

Within the health care system, patient education occurs in a health care professional's office, clinic, hospital, community health centre, or in a person's home. System barriers to learning may exist in each of these environments. For example, in an office or clinic, the health care professional controls all aspects of the clinical situation, including when, where and how patient education takes place. If a patient wants to see a health care professional, the patient must make an appointment, and the timing of this appointment depends on the health care professional's availability more than the patient's availability.

The life-world consists of the informal, everyday interactions of daily life, and the system consists of structures based on money and power such as corporations and governments that have an impact on the life-world. These structures do more than intrude into the life-world — they oppress it (Merriam & Caffarella, 1999). Valued knowledge is centered on the economic, political and social interests of emancipation or domination. Predetermined goals or outcomes, which are socioculturally defined, indicate that the learner has very little personal control over the educational experience (Usher, Bryant, & Johnston, 1997).

This may occur in patient education interactions, due to the fact that health care professionals use a medical conception of care and treatment as a consequence of their orientation, schooling, and socialization (Hydén & Mishler, 1999). This may result in the medical conception of illness being used as a basis for patient education, despite potential conflict with the life-world of the patient.

Critical theory's strength lies in its critique of existing economic and social structures and resultant identification of power dynamics that affect learning. Its weakness may be in considering individual factors, such as the learners' feelings, that may shape the meaning of the educational experience. Such factors may be more amenable to change, at least in the

short term. Also the individual's reaction or opposition to power is not taken into consideration in critical theory. The assumption is that the individual is consenting and may in fact be interacting with the power over them. This may not be the case. It would be assumed that the majority of adults, if aware of this power over them, would resist it if they felt that it was harmful to them.

The intent of critical theory is a just society. Welton (2005) has recently proposed that changes in the "global economy and social systems have created severe problems for the realization of a just learning society" (p. 19). This is expanding the system to not only the national structure that an individual lives within but the international influences. Therefore adult learning experiences can be viewed in relation to social movements.

This expansion to national and international influences can lead to difficulties when researchers attempt to investigate and identify the oppressors of knowledge who have power over an individual. Researchers themselves can actually become a type of oppressor because of the choice they make in methodology. Freire (1970) cautioned against treating ideas of empowerment and oppression as specific methods for social change. The concern is that the larger socio-economic interest of power behind the findings will be clouded over by the individual's situation. The result would not be able to expose the power that society has had over that individual.

Summary of Adult Learning Theories

Transformational learning theory, situated cognition, and critical theory complement each other. Transformational learning theory (Mezirow, 1995), with its emphasis on the individual learner and learning as an internal cognitive process, may be useful to understand how learners' individual characteristics, including literacy ability, have affected their patient education experiences. Situated cognition theory (Kirshner & Whitson, 1997) shifts attention

from the individual as a learner, to the learner as a participant in the social world and an integral member of a community of practice. This theory may be useful to understand the role of the health care environment and the literacy classroom on the participants' patient education experiences. Critical theory (Welton, 1995a) connects adult learning to the ideals of emancipation, democracy, and community empowerment to encompass all members of society. Critical theory may be useful to understand how the health care system influences the participants' patient education experiences.

CHAPTER THREE-RESEARCH METHODOLOGY

The purpose of this chapter is to outline the research methodology used in this study. Within this chapter is a description of the research approach, the researcher's background and assumptions, research purpose and questions, research design, sampling, setting, research participants, data collection procedure and tools, and the data analysis path. Finally, this chapter discusses the trustworthiness of the research and provides a summary of the research method.

Research Approach

A qualitative research design was selected to learn about how individuals with limited literacy and chronic illnesses experience patient education. This experience had not been documented previously and it was anticipated that the issues were going to be very complex and multi-layered. Data collection was therefore open to all of the ways that people take meaning from their experiences, give meaning to their experiences, and learn in these experiences. Yet, the research maintained its primary focus of uncovering the actual experience of patient education for individuals by using an inductive, interpretive, hermeneutic phenomenological method (van Manen, 1997b).

Edmund Husserl, a German philosopher, is often considered to be the founder of phenomenology. He sought to establish a science of the cognition of essences rather than of matters of fact. Husserl's phenomenology came to mean the study of phenomena as they appear through consciousness. Its base is in epistemology and emphasizes a return to reflective intuition to describe and clarify experience as it is lived and constituted in consciousness (Husserl, 1970).

Phenomenology derives from the Greek word phenomenon, which means to show itself or to put into light or manifest something that can become visible in itself (Heidegger,

1958). The experience of things or phenomena “include sense perception (seeing, hearing, touching, tasting, and smelling) and other phenomena, such as believing, remembering, anticipating, judging, intuiting, feeling, caring, loving, imagining, and willing” (Ray, 1994, p. 127). Spiegelberg, a historian of the phenomenological movement, noted that “phenomenology is the direct investigation and description of phenomena as consciously experienced, without theories about their causal explanation and as free as possible from unexamined preconceptions and presuppositions”(Spiegelberg, 1965, p. 659).

Husserl (1970) introduced the concept of lived experience or the life world. This term emphasizes the importance of individual lived experiences of people as conscious human beings (Moustakas, 1994). Studies of phenomena usually describe the meaning of certain lived experiences of several people, not just one individual. In such work, the researcher must “enter the field of perception of the participants; seeing how they experience, live and display the phenomenon; and looking for the meaning of the participants' experiences” (Creswell, 1998, p. 31). Ideally, the result is both an “expansive deepening of our level of consciousness and broadening of our range of experiences” (Merriam & Simpson, 1995, p. 90) and an understanding of the central meaning or “essence” of the experience (Moustakas, 1994). Husserl (1970) noted that there were universal essences. Essence is the “essential, invariant structure of the central underlying meaning of the experience” (Creswell, 1998, p. 52).

Husserl's work is usually categorized as transcendental phenomenology. Husserl's student, Martin Heidegger (1889-1976), expanded and altered some of Husserl's teachings by developing hermeneutic phenomenology.

Hermeneutic Phenomenology

Hermeneutics is derived from the Greek word *hermeneia*. The Greek root is

“bringing to understanding particulars where the process involves language” (Leonard, 1989). Hermeneutics generally refers to the art, theory, and philosophy of interpretation of the meaning of an object (a text, a work of art, human action).

Hermeneutic phenomenology comes from philosophical hermeneutics. Philosophical hermeneutics is a postmodern philosophy which has emerged to occupy a prominent place in the consideration of existential issues (Thompson, 1990). Hermeneutic phenomenology is an interpretative approach and is an “ontologic way of being in the social-historical world where the fundamental dimension of all human consciousness is historical and sociocultural and is expressed through language (text)” (Ray, 1994, p. 118).

Van Manen (1997b) believed “that hermeneutic phenomenological method is not a procedural system but rather its methods requires an ability to be reflective, insightful, sensitive to language and constantly open to experience” (p. xi). Van Manen joined the transcendental (descriptive) phenomenology movement with the hermeneutic (interpretive) phenomenology movement. The joining of the two movements is based on the work of the Dutch phenomenologists from the “Utrecht school,” such as Langeveld, Buitendijk, and Linschoten (Cohen & Omery, 1994). Van Manen has proposed that research in the human sciences cannot be separated from the textual practice of writing. According to van Manen (1997b), hermeneutic phenomenology research is “seen as a dynamic interplay among six research activities” (p. 30). These research activities include the researcher's interest in the phenomenon, investigation of the participants' lived experience, and reflection on the themes with characterizes the phenomenon. The research activities also include a description of the phenomenon in written form, maintaining a strong and oriented pedagogical relation to the phenomenon, and balancing of the research context by considering the parts and the whole (pp. 30-31). Stanage (1987), an American philosopher and adult educator, described

phenomenology as one of meaning and values which must be addressed by any theory of adult or lifelong learning. He stated that phenomenological investigations in “education opens up new directions for research and uncovers new layers of clarity in perception, conceptions, action, and practices” (Stanage, 1987, p. 45).

Denzin and Lincoln (1998) have stated that “qualitative research is only as good as the investigator” (p. 66). This is certainly the case in phenomenological inquiry. If a researcher fails to understand how concepts and methods of data gathering and inspection relate, the study might yield phenomenological positivism (Bolton, 1987). If the researcher does not communicate his or her own philosophical stance of phenomenology in the research report, this may call into question the study's credibility.

Researcher's Background and Assumptions

Bracketing of assumptions and pre-understandings is central to hermeneutic phenomenology. Bracketing allows the researcher to be aware of his or her beliefs and try to understand their influence on the research process. It allows the researcher “to bring into focus the uniqueness of the particular phenomenon” (van Manen, 1997a, p. 350). It is also seen as a way to become open to seeing the world differently. To come to this point, the researcher must come to an understanding of how he or she conceptualizes the phenomenon before beginning the inquiry. The researcher's assumptions are stated at the beginning of the research process and reflected upon throughout the research process.

The assumptions that I brought to this research endeavor were rooted in my experiences as a physiotherapist, my views on literacy and health, patient education and chronic illness, and from my experiences working on another research project with adults with limited literacy. My educational background includes a Bachelor of Health Sciences in Physiotherapy and a Master's of Health Sciences. As a physiotherapist over a time span of 18

years, I have worked in a number of different settings, including large teaching hospitals, rehabilitation centres, and Canadian universities. My clinical focus for the last decade has been treating adults with chronic illnesses, specifically heart and lung problems, such as asthma, emphysema, and high blood pressure.

My role as a physiotherapist includes answering patients' questions, helping them understand their illness, and providing advice so that they can manage their condition by themselves. I believe that I had to be cognizant of the fact that during my PhD studies and my interactions with participants, my role was one of a researcher and not of a clinician. This was a challenge, as it is second nature for me to give health advice when people discuss their health problems.

Another area in which I brought both experience and presuppositions is in the content area of literacy and health. I first became aware of the topic of literacy and health in 1999. It was in that year that I was asked to represent the Canadian Physiotherapy Association on a National Literacy and Health Partnership (NLHP) of the Canadian Public Health Association. This partnership is made up of 27 national literacy associations and national health professional associations. The NLHP mandate is to increase health care providers' awareness of the effects of limited literacy on the health of Canadians. Through my involvement with the NLHP, I became aware of the prevalence of limited literacy in Canada and the serious effects that limited literacy can have on health. I assume that many health care providers are as unaware of this issue as I was. I believe that, due to a lack of awareness of the extent of limited literacy among their patients, and failure to appreciate that many of their patients may have low literacy, they may not consider low literacy as a reason for patients not following their advice. They may unwittingly label such patients as noncompliant or as "difficult patients" when the real issue is one of limited literacy.

From my experience working in the health care system, I also believe that there continues to be a power imbalance between patients and health care professionals. I believe that some patients still regard health care professionals as God-like; these patients are fearful of asking questions or disagreeing with advice. I also think that some health care professionals encourage this attitude, believing that patients should just follow their instructions and never question their advice.

The other area in which I brought previous experience and opinions is patient education. In terms of patient education, I believe that most health care professionals try to teach their patients how to manage their illnesses and assume more control for their own health. I know that a lot of time and money is spent on patient education and I believe that most health care professionals are ineffective in their teaching because they do not approach patient education in a systematic way. This may be due to the fact that effective patient education strategies are not highlighted during the training of most health care providers. In my opinion, the one professional group that does do an effective job in delivery patient education is the nursing profession. Of all health professionals, nurses are probably the best trained in providing patient education because of the emphasis that patient education methods appear to have in their professional curricula. I know that in physiotherapy, my own profession, it appears that very little time is spent teaching students strategies and principles of effective patient education in the curricula of any one of the 13 Canadian programs.

Due to my experiences working with people living with chronic illnesses, I assumed that most people with chronic illnesses interact with many different health care professionals. I assumed that most of the health care professionals that they encounter provide them with information to help them deal with living with their disease. I also assumed that individuals living with chronic illnesses would be seeing a physician on a regular basis that specializes in

their chronic illness. For example, someone living with asthma would see a respirologist. I also assumed that the patients would be in contact with a family doctor, a pharmacist, and nurses on a regular basis throughout the year. I assumed that due to their chronic illnesses they would also have had health care interactions with rehabilitation professionals, such as a physiotherapist or an occupational therapist, and that some of the participants would have also seen a dietician, a social worker, and/or a psychologist to help them manage their chronic illness.

My experience working with adults with limited literacy on a previous research project lead me to think that, similar to most research projects that involve human participants; this study would provide some challenges in terms of data collection. One of the main challenges I assumed that I would encounter would involve scheduling and coordinating interviews with the participants. I assumed the participants would be adults with complex lives which would involve trying to juggle going to school, raising a family, and coordinating their medical appointments. I assumed that sometimes they would be present at scheduled interview times and other times we would have to reschedule. I therefore needed to have a flexible schedule during the data collection phase. I believed that interviewing adults with limited literacy about their health involved building a trusting relationship, so that the participants were comfortable talking about this personal topic.

Also from my previous experience working with adults with limited literacy, I became aware of the nature of literacy itself. I realize that literacy is much more complex than just the ability to read and write. Instead, it is more of a concept than a definition. I hope that, through my research findings, I can gain insight into how health care professionals, myself included, can do a better job providing patient education to people with limited literacy.

Purpose and Research Questions

The overarching question guiding this inquiry was: What is the meaning of patient education experiences for adults with limited literacy and a chronic illness? Two secondary questions were: (1) How do patient education experiences affect adults with limited literacy and a chronic illness? and (2) What are the barriers that adults with limited literacy and a chronic illness encounter in patient education experiences?

This study explored the experiences of patient education by participants who are living with limited literacy and a chronic illness, allowing their voices to be heard.

Research Design

Purposeful Sampling

A characteristic of the purposeful selection of participants in phenomenology is that the potential participants need to be carefully chosen to ensure each has experienced the phenomenon. For the purpose of the study, potential participants needed to have limited literacy and a chronic illness. Morse (2000a) states that 6 to 10 participants should be sufficient to allow the discovery of the essences from experience by gathering adequate detail and depth in a phenomenological inquiry. Morse (2002) also suggests that this number should be increased if any of the participants feel awkward talking about the topic under study. Discussing patient education experiences may be difficult or awkward for the participants because, for most people, health issues are a very private and personal topic.

Setting

To help the reader understand the context in which the participants live, the setting of the study will be described in detail. The setting for this study was community based Literacy and Basic Skills programs in a city in Eastern Ontario. In describing this setting I

will look at each of these levels in turn, beginning with the broadest which is the city and moving towards the most specific of the LBS programs.

City

This study occurred in a city in Eastern Ontario. The workforce includes a high percentage of government, high technical-computer jobs, and health care workers. Compared to other cities in the country, this city has the highest per capita concentration of engineers, scientists, and PhDs. Approximately 8% of the population over 20 years of age does not have a high school certificate. This city also had the highest median annual household income of any Canadian city in 2001, at \$73,507 (Statistics Canada, 2005a).

This city is a multicultural and multilingual community. Approximately 66% of the 2001 population spoke English at home while 13% spoke French. The other most common languages spoken at home are Arabic (0.9%), Vietnamese (0.4%), Cantonese (0.3%), Spanish (0.3%), Italian (0.3%), and Farsi (0.2%) (Statistics Canada, 2005a).

There are numerous hospitals within the health care system, including a large multi-site teaching hospital, which includes a rehabilitation centre and a specialized facility providing mental health care. The city also has an extensive Public Health Department that provides services to all inhabitants through programs geared towards public health issues, such as reducing obesity, improving air quality, and maintaining food safety.

The faculties of Medicine and Health Sciences at the university educate clinicians in medicine, physiotherapy, and other health care professions. Research on health and health services is carried out by faculty members at this university and associated research institutes.

Clearly, this city has a high concentration and diversity of health care activity. Although there are issues of waiting times for people living in the city, the participants in this

study would likely have had the potential to access a wide range of medical specialists to assist them in managing their chronic illness.

The Literacy and Basic Skills Programs

LBS programs in Ontario are delivered through community colleges, school boards, or local literacy organizations. Within the city, the English language LBS programs are offered by the local community college, literacy organizations, and the local school boards.

The participants in this study attended either one of two community based literacy programs, which will be named Alpha and Beta. The two LBS programs have some similarities and some differences. The similarities will be discussed and then the differences will be presented in the two following sections that deal with each LBS programs individually.

In addition to LBS programs, community based programs offer English as Second Language (ESL) programs. The ESL programs often feed into the LBS programs. That is, when ESL students with limited literacy reach a certain level of English proficiency, as assessed by the literacy coordinator, they are referred to the LBS program by their ESL teachers. These students then enter classes that include students whose first language is English. Once admitted to the LBS programs, students are no longer considered ESL students.

Classrooms include adult learners who have different levels of literacy ability; this is referred to as multilevel classroom. This is due to two administrative policies of the LBS programs. The first is that students enter the programs on a continuous basis; therefore each classroom contains students who have attended the class for a longer period time and are thus likely to have more advanced literacy ability. The second policy derives from the provincial policy that each student will have an individual training plan developed from the learning

outcomes matrix. Consequently, it is unlikely that any two students would be at the exact same level in each of the learning outcomes at the same time.

Many of the students attending LBS programs are unemployed and are receiving social assistance from the Ontario Government, through the Ontario Works program and Ontario Disability Support Program (ODSP). Ontario Works is a temporary financial assistance program offered by the Province of Ontario, which is funded through the Ministry of Community and Social Service (2005a). As a condition of receiving funding, recipients are required to participate in employment preparation activities. One of these activities is attending LBS classes (Ministry of Community and Social Services, 2005b).

The ODSP is also funded through The Ministry of Community and Social Service (2005a). To receive ODSP income support, the person must have a “substantial physical or mental impairment that is continuous or recurrent and is expected to last one year or more” (Ministry of Community and Social Services, 2005b, para 3). This impairment is determined by a health care professional using criteria established by the Ontario Government (Ministry of Community and Social Services, 2005c). The aim of this program is to help people with disabilities become more independent through direct financial support and employment support, including training at LBS classes which will help them get and keep jobs which also include training. To qualify for employment support, the person must be willing and able to work in Ontario.

Alpha program.

The Adult Literacy and Basic Skills Program is part of the Continuing and Community Education Department. This department also includes the programs in International Languages, and English as a Second Language for Adults. The curriculum of the LBS program of the department is designed to provide quality literacy, numeracy, and

basic skills instruction to adults living within the rural and urban communities in order to help them meet their goals for work, further education, community involvement, and independence.

The LBS teachers that work within the Alpha program have two levels of qualifications. Level 1 requires a university degree and additional experience in teaching adults as well as an Adult Literacy and Basic Skills Certification. Level 1 teachers provide instruction to students in the LBS classrooms. Level 2 requires a person to have Ontario teaching qualifications and to be registered to teach with the Ontario College of Teachers. Level 2 also requires two additional qualification courses of Special Education Part 1 and Reading Part 1, Adult Education. As well, for a Level 2 designation, the person must have a Master's degree with a specialization in adult literacy or equivalent qualifications as determined by the program management. Level 2 teachers may teach LBS students but they are often in positions of administration and program development, such as the LBS coordinator's position for the Alpha program.

Within the Alpha program, at the time of this study, the LBS classrooms were located in nine different sites including community centres, churches, and schools. Usually the classes were held during the day Monday to Friday, but some of the programs ran only Monday to Thursday. The participants attended 8 to 15 hours per week of LBS classes.

Beta program.

The Beta program refers to its LBS program as the Employment Preparation and Upgrading Program. Similarly to the Alpha program, its LBS program is part of Continuing Education. The Continuing Education division also includes ESL programs, LBS programs, and International Language programs.

The Beta program was designed to meet the learning goals and literacy needs of the adult students who have not completed a high school education. The curriculum has two main streams: employment preparation programs and upgrading programs. At the time of the study, the program offered three options for students to accomplish these goals: (1) an employment preparation program geared toward the ultimate goal of part-time or full-time employment for the students; (2) an upgrading program to help the students gain academic credentials therefore allowing them to enter a high school credit program, pass a community college entry test, or acquire a graduate equivalency diploma (GED) and; (3) a program which prepared adults with developmental disabilities for workplace and volunteer positions.

To teach in the LBS program a person must have Ontario teaching qualifications and be registered to teach with the Ontario College of Teachers; this is the same requirement for all teachers throughout the Beta program. Some of the LBS teachers have had teaching experience within the elementary or secondary school system and some have also had some experience teaching in ESL classes.

At the time of this study, the literacy classrooms were located in a traditional high school building which was centrally located in the city. The classes were taught from Monday to Friday for three hours per day for a total of 15 hours a week and for three hours a week on Monday evenings to accommodate students who had full time jobs.

Ethics and Access to Participants

After approval of the research proposal from the Faculty of Education, ethical approval for this study was requested from the Social Sciences and Humanities Research Ethics Board (SSHREB) of the University. As well as the university approval, ethical approval was also requested from the Alpha and Beta Programs, Research Advisory Committee, which approves all research activities in the LBS programs. Ethical approval

was granted by both organizations (Appendix A). Upon gaining both ethical approvals, I sent a letter of introduction and invitation to the literacy coordinators of both programs (see Appendix B). After meeting with each of the literacy coordinators to discuss the best method to contact possible participants, it was decided that I would present the purpose of my study at staff meetings of the literacy instructors. This was done during two staff meetings in the fall of 2003, one at each program. The literacy instructors had an opportunity to ask me questions and to make suggestions regarding the best ways to approach potential participants. The literacy instructors asked me to contact them by email to plan times to visit each of the classrooms without disrupting the flow of the class.

Recruitment

I visited seven individual classrooms, each with a different instructor and under the jurisdiction of one of the two programs. I presented myself and the purpose of my study to the students and answered questions. Many of the instructors had already read out the letter of introduction that described the study for the instructors and students. The students asked questions regarding the types of health problems that would make individuals eligible for the study. I explained that I was looking for students who had long-standing health problems and used the examples of asthma, diabetes, high blood pressure, arthritis, or any other physical problem that they had had for at least 6 months.

After responding to their questions, I gave the students my business card in case they wanted to call me and privately ask me questions about the study. No participants contacted me in this manner. I returned to the classrooms a few days later to see if any of the students were interested in participating in the study. I returned at the end of the school day for the class so that other students would have left before potential participants approached me. In this way, non-participants would not know who the participants were. The participants were

selected based on the following criteria: (a) availability; (b) over 18 years old; (c) willingness to describe the experience of patient education, in English; and (d) diagnosed with a chronic illness.

When a student agreed to be part of the study, we set up a time that was convenient for them to be interviewed. All interviews began with a review of the study and the signing of the consent form before any data was collected. Written consent was obtained from each participant (see Appendix C). If a participant preferred, I read the consent letter aloud and explained any words or concepts as requested. Three participants asked me to read the letter aloud; none of them asked me to explain any words. All participants mentioned that the letter was very clear and that they understood what the study was about and what I would be discussing.

Sample

Taking the before mentioned selection criteria into consideration, 14 adult participants were selected from LBS programs offered in the city. Nine participants were from the Alpha program and five participants were from the Beta program.

The nine participants from the Alpha program were students in three different classrooms. Two of these classrooms were located in two different churches and the other classroom was located in a former elementary school. Of the nine participants, three participants attended the same class in one of the churches, three others attended the same class in the elementary school, and two of the participants attended the same class in another church. The five participants from the Beta program attended four different classrooms, including one who attended the evening program. By chance, the participants were members of each of the different types of LBS programs offered by the Beta program.

Data Sources and Data Collection

Morse and Richards (2002) comment that there needs to be methodology congruence between research questions and data sources and collections (p. 33). The data sources in phenomenology are "the phenomena or more precisely the conscious experience of phenomena" (Merriam & Simpson, 1995, p. 91). These can include material objects such as a work of art, photographs, or a videotape recording (Ray, 1994). Because lived experience is critical to phenomenology, it is important that the data sources are in tune with these experiences. Therefore the main data sources are individuals who have experienced the phenomena itself. The phenomena is probed until the experience is illuminated and described using a variety of data sources including field notes, a research journal, and interviews (Creswell, 1998). Three data sources were used for this study: 1) semi-structured interviews, 2) field notes, and 3) a researcher's journal.

Pilot Study

Any type of research involving adults with limited literacy requires particular mindfulness regarding appropriateness of data collection tools. Therefore, a pilot study involving one participant was undertaken to reveal any concerns with the consent form, demographic form, interview guide, and the interview approach.

The participant was a 55-year-old man named Pierre (a pseudonym). Pierre quit school when he was 15 years old and was attending the LBS classes through the Alpha program for the last five years. He was receiving a disability pension through the ODSP following a car accident 10 years ago that had left him unable to work at his job in a lumberyard. As a result of the injuries he sustained in the car accident, Pierre had been living with chronic pain for approximately nine years. He also had been diagnosed with arthritis

approximately five years ago. He lived alone in an apartment and relied on his sister and brother-in-law to help him fill out forms when he attended health care appointments.

The interview took place in a separate private room at the school where the participant was attending class. I began the interview by reviewing the study objectives and methods. Pierre read and signed the consent form and did not ask for any clarification of words. An interview schedule was used to provide some structure in which to explore the patient education experiences for the participant. With a hermeneutic research approach, interview questions can be formed using "conceptual, theoretical, or historical traditions" (Ray, 1994, p. 129). Therefore, the interview schedule included 12 guiding questions based on different aspects of patient education. For example, the participant was asked questions such as, "Are there puzzles that you do not know about your illness?" and, "how would it be most helpful for your health care provider to share information with you?"

The interview was tape recorded and lasted approximately 30 minutes. I transcribed the audiotapes using standard conventions of transcription as suggested by Sandelowski (1994). Both during the interview and following the transcription I realized that some of the guiding questions were too vague or even confusing. Upon listening to the audiotape, I noted that the participant had asked me to clarify what I meant for a number of the questions. As well, I observed that for some questions, the participant had answered with only a yes or a no, providing little information.

As a result of this interview, significant changes to the following collection tools were made to both the interview schedule and the demographic form. The demographic form was expanded to allow for recording of more contextual information, such as the number of years the participant had been attending classes in the literacy and basic skills program (see Appendix D).

I also made substantial changes to the interview schedule after the pilot study. I realized that I needed to add more probing questions to my overall guiding questions and that I needed to add questions about the learning aspects of the experience of patient education for the participants. For example, the interview guide for the pilot study contained the question, “How would it be most helpful for your health care provider to share information with you?” I kept this question in the final interview schedule but added questions before this such as, “What kind of health information, patient education, or advice do you need to help you deal with your illness and take good care of yourself?”

The questions were grouped into different categories. These categories, drawn from the adult education and patient education literature, represented the different aspects of patient education. The categories were the different formats of patient education, written and verbal, and the different components of patient education experiences such as setting and group learning. Finally, a field note form (Appendix E) was developed following the pilot study to record specifics of the interview, such as time and place, to help to maintain consistency between the first and the second interviews.

First Interviews

The interviews were seen as conversations with a purpose. All interviews began with a review and signing of the consent form as well as the completion of the demographic form (Appendix C). Interviews were conducted with each participant using the revised interview guide (see Appendix F). The average length of time for the first interviews was approximately 45 to 60 minutes. Some interviews were as brief as 30 minutes while the longest lasted 90 minutes. The participants were given the choice to either be interviewed at school after their class was finished for the day, or in their homes. All first interviews occurred at the site of the literacy programs, in a private room, with the door closed, and with

only the participant and me present. These interviews also served to start to build a relationship with the participants; to establish a base of trust from which personal and possibly sensitive topics could be further explored. The questions from the first interviews were focused on a descriptive level of patient educational experiences. Questions concerned such areas as written patient education and verbal patient education experiences.

Patient Education Written Material

Patient education written material was used as a visual prompt within the interviews to further explore participants' experiences with patient education written material. Examples of patient education written material were chosen to represent the different types of common patient education material that participants might have encountered in their interactions with health care professionals. Prior to the pilot study, I had planned to ask participants to bring in patient education material that they had received from health professionals. However, the participant in the pilot study told me that he always discarded this information. He told me that once he read the information, he knew it and didn't want to have "the paper hanging around." I thought this might be the case for other participants as well. I therefore decided to provide the patient education material for the interview. This material included information about an antibiotic medication, a general health promotion handout, and three handouts describing specific diseases and their management.

The information about the prescription antibiotic medication was from a local pharmacy. It was a two-page document that the pharmacist gave to every patient who was prescribed this medication. The document consisted entirely of text; there were no diagrams or pictures. The document listed how to take the medication, side effects, precautions, and drug interactions. A general population health promotion pamphlet was also used, *The*

Canadian Physical Activity Guide from Health Canada (Health Canada & Canadian Society for Exercise Physiology, 2001). The pamphlet was a one page multi-coloured document, with drawings of people doing different physical activities such as bike riding and mowing the lawn.

Three specific patient education disease-related materials were also used with each participant. One of the pamphlets was entitled *Asthma: Learning to control your symptoms* (The College of Family Physicians of Canada, 1997). This pamphlet was designed in a question and answer format. The questions included: “What is asthma? Will asthma limit what I can do?” It also included a description and a drawing of how to take a bronchodilator, a medication commonly used in the treatment of asthma. Another pamphlet dealt with cholesterol and heart disease and was designed with a checklist of risk factors on the front page. This pamphlet was part of the series “The Healthy Heart Kit” and was entitled *Cholesterol and heart disease: How to control your blood cholesterol and reduce your risk of heart disease* (Health Canada, 1999a). Within the pamphlet were six sections on strategies to control blood cholesterol. The final patient education material that was used was a 22-page booklet entitled *Living well with COPD: Chronic Obstructive Pulmonary Disease* produced by The Lung Association (The Lung Association, 2002). This multi-coloured booklet provided information on topics of smoking and lung function, symptoms of COPD, medications, breathing techniques, energy conservation, nutrition, exercise, sleep, and sexuality related to living with COPD.

Narratives

Following the transcription of each interview, narratives were compiled for each participant from each interview. The narratives were developed from the transcripts and demographic information that was collected at the interview. The narratives were written

using a story-like format and included specific quotes from the participants. I met with each participant following the first interview and provided them with a typed, double spaced narrative.

The narratives were, on average, eight pages long. As a method of member checking, as recommended by Lincoln and Guba (1985), the participants reviewed and commented on the narratives. Member checks will be described further in the trustworthiness section of this chapter. The participants read their own narrative or, if the participants preferred, I read the narrative to them. Any needed changes were made to the narratives before analysis of the narratives ensued.

Second Interviews

Once the analysis of the first interviews was completed and themes uncovered, participants were asked to participate in a second interview. I felt that a second interview was needed to allow me to delve further into areas that emerged from the first interviews following the preliminary analysis. All 14 participants agreed to a second interview and all participated. The second interview schedule is found in Appendix G. There were approximately 10 to 12 questions under each area that acted as probes to help expand the topic areas. Again, following the second interview, the audiotapes were transcribed and the transcripts were used to form narratives. Member checks occurred using these narratives at another time. This meeting occurred after the second interviews took place. The second narratives were, on average, six pages long. Changes were made to the second narratives as needed.

All but three of the second interviews and members checks occurred on site at the literacy program. For three participants who were no longer attending the literacy programs, their second interviews and subsequent member checks occurred in their homes. Two

participants had left the literacy programs due to decreasing health status. One participant left the literacy program after obtaining a full-time job.

Field Notes

Field notes were maintained throughout the study and consisted of the “raw” data that, as suggested by Schwandt (1997), was based on observations and conversations in the field. A form was developed to record this information. Notes were taken before and after each interview to document specifics such as location, the time of the interview, and the changes made after member checks. This field note form also allowed me to record observations such as my impressions of how relaxed or nervous the participant appeared to be during the interview.

Researcher's Journal

A researcher's journal was kept throughout the study. It was used during all phases to facilitate self-awareness through documentation of my perceptions, observations, feelings, and insights during the research process as recommended by Streubert and Carpenter (1999). The journal outlined the rationale used for decisions made concerning the collection, coding, analysis, and interpretation of the data as suggested by Miles and Huberman (1994). The entries in this personal reflective journal were dated and kept separate from other field notes.

Data Analysis

Data analysis is a reflective process and involves a sensitive attunement to opening up to the meaning of the experience (Ray, 1994, p. 129). Creswell (1998) suggested that “phenomenological data analysis proceeds through the methodology of reduction, the analysis of specific statements and themes, and a search for possible meanings” (p. 52).

In this study, data analysis occurred concurrently with data collection and interpretation. Atlas-ti (version 5.0), a computer software program, was used to help with

data management. The software manages the data but does not actually analyze it. I also began writing my descriptive as well as my interpretative findings at the same time. I wanted to make sure that I did not miss anything, so I still relied on paper versions of the data to reread and reflect upon. To this end, I made many copies, highlighted them with pens and markings, as well as used the print outs from Atlas-ti. I used the seven procedural steps outlined by Colaizzi (1978, pp. 59-62) for data analysis in phenomenological studies:

1. Read the participant's descriptions of the phenomenon in order to acquire a feeling for them.
2. Return to each participant's original transcript and extract significant statements.
3. Try to spell out the meaning of each significant statement, by being involved in creative insight, going beyond what is given in the original data and at the same time staying with it.
4. Repeat step 3 for each participant and organize the aggregate formulated meanings into clusters (categories); that is allow for the emergence of themes which are common to all of the participants' transcripts; always referring back to the original transcripts.
5. Integrate the results into an exhaustive description of the phenomena.
6. Formulate the exhaustive description of the investigated phenomenon in as unequivocal statements of identification of its fundamental structure as possible.
7. Return to the participant, ask about the findings thus far, and incorporate any new data that emerges from these interviews into the final product.

Representing the Data

Within the final write up of a phenomenological study, there is often a textural description as well as a structural description of the results. The textural description is what

was experienced and the structural description is how the phenomenon was experienced (Creswell, 1998, p. 55). The textual description includes the extraction of categories and themes from the data. A theme is the sense we are able to make of something; it is the process of insightful invention, discovery, and disclosure (van Manen, 1997b). The textual description is found in Chapter 4. As well, the researcher develops an overall structural description of the experience or the essence. These rich descriptions of individual experiences will serve as the basis to incorporate the background meanings provided by the theoretical perspectives of the adult learning theories and the literature in literacy, literacy and health, and patient education. It is these descriptions that give lived quality and significance of the experience to provide a deeper and richer understanding of the experience (van Manen, 1997b). The structural description of the experience is found in Chapter 5. I have chosen to proceed to tell the story of this thesis through separate chapters instead of integrating the textual and structural description of the essence into one chapter. I believe that this allows for a more extensive exploration and understanding of the meaning of patient education experiences for adults living with limited literacy and chronic illnesses.

Trustworthiness

Qualitative research provides unique and wonderful opportunities to gain insight and understanding of the lived experiences of people. One of the key reasons to undertake a research study is to share these insights with others. This sharing usually requires that the reader will trust that the researcher has undertaken the study in a rigorous fashion. Trustworthiness is used to establish the rigor of the research endeavour. Because “without rigor, research is worthless, becomes fiction and loses its utility” (Morse, Barrett, Mayan, Olson, & Spiers, 2002, p. 2).

According to the positivist quantitative paradigm, there is one ultimate truth and this truth can be found through research. Therefore, a research study is valid if it is able to measure and record this truth. The epistemological definition follows the axiom of the subject-object dualism, where there is seen a distance between the observer and the observed and that the observer is able to observe without interfering with the results. In qualitative research, there are multiple truths which are co-constructed by the investigator and the participants. This is a subjective epistemology that the observer and observed create understandings together.

In their book "Naturalistic Inquiry," Lincoln and Guba (1985) acknowledged that establishing trustworthiness in qualitative research is a different concept than establishing validity in quantitative research. They therefore believed that qualitative research should not use the same terminology as quantitative research. Although more recently authors have begun to use the term validity in qualitative research (Creswell, 2005), there still exists confusion in the literature about the conceptual definition of validity for qualitative research. I have thus decided to use trustworthiness.

The four key areas that quantitative researchers use to establish the validity or usefulness of research are truth value (the findings reveal the "truth"), applicability (the findings can be used in other settings), consistency (the findings are similar to previous studies) and neutrality (the subject-object dualism). Lincoln and Guba (1985) suggested the use of alternative terms of credibility, transferability, dependability, and confirmability. Each of these four terms and the sources of trustworthiness in this study will be discussed in the following section.

To ensure credibility, the researcher must show that he or she has represented multiple constructions of reality adequately (Lincoln & Guba, 1985). Activities used to increase the probability that credible findings were produced from this study were the use of purposeful sampling, the interview guide, member checks, and triangulation of the data as suggested by Lincoln and Guba (1985) and Creswell (2005).

Transferability

Transferability concerns whether the findings of a study can be applied to other settings (Creswell, 1998). Individuals familiar with the context of the other setting must make this determination. Therefore, it is essential that the researcher provide enough details regarding the study, participants, and setting, so that readers can determine whether or not the findings could be applicable or transferred to their own setting (Lincoln & Guba, 1985, p. 316). As suggested by Lincoln and Guba (1985) as well as Morse (2002), rich, thick descriptions were used in this study to ensure the level of detail required to help with transferability. These descriptions were found in both the participants' profiles which described such things as participants' ages, types of chronic illnesses, years living with their chronic illness, and the descriptions found in the findings section of the thesis.

Dependability

Dependability focuses on the "process of the inquiry and the inquirer's responsibility for ensuring the process was logical, traceable and documented" (Schwandt, 1997, p. 164). Therefore, the qualitative researcher must "seek means for taking into account both factors of instability and factors of phenomenal or design induced change" (Lincoln & Guba, 1985, p. 299). The means or procedures to do so for this study included the use of an audit trail including instrument development information and triangulation as suggested by Lincoln and Guba (2000). Keeping field notes and audiotaping the interviews also increase the

dependability of the findings because they provide a record of the raw data (Guba & Lincoln, 1998).

Confirmability

Lincoln and Guba (2000) believe that objectivity "is a chimera: a mythological creature that never existed, save in the imaginations of those who believed that knowing can be separated from the knower" (p. 181). They therefore use confirmability to indicate that the reader can confirm the findings but that the findings are not objective or neutral. In this study, an audit trail, which includes the researcher's journal, as well as the use of triangulation, was essential in ensuring confirmability of the findings. The sources of trustworthiness for this study therefore included member checks, detailed thick, rich descriptions, an audit trail, and triangulation.

Member Checks

According to Lincoln and Guba (1985), member checks are the most important technique to establish the credibility of a study. Member checks give participants an opportunity to correct errors while allowing the researcher to assess for intentionality of what the participants said or meant to say. It is not a technique to verify the overall results of the study but more of a method to establish trust with the participants and verify data both within and among participants (Morse & Richards, 2002). As mentioned previously, member checks in this study followed each of the interviews. The member checks allowed the participants to further clarify and expand upon comments from their interviews and their patient education experiences. The member checks also allowed me to add missing components to the demographic form.

Colaizzi (1978) advocates that the researcher must return to the participants to validate that the findings reflect their own perceptions of their experience. This is not just a

member check that the information from the interviews is correct but that the researcher's description and interpretation of the experience match the participants' interpretations.

Detailed Thick Rich Descriptions

As noted above, detailed thick and rich descriptions allowed for transferability of the research findings. In this chapter, I have presented a description of the research setting and in chapter 4; I will present detailed information about the participants of the study. It has been challenging to provide thick rich descriptions of the participants and their settings without betraying the confidentiality of either the participants or the research setting. However, I believe a good balance has been struck.

Audit Trail

In an audit trail, the researcher carefully documents the conceptual development of the project, thus allowing others to reconstruct the process. The audit trail suggested by Halpern (1983) and reported in Lincoln and Guba (1985), consists of six types of documentation. They include: raw data, data reduction and analysis products, data reconstruction and synthesis products, process notes, materials relating to intentions and dispositions, and instrument development information.

In this study, the raw data included the audiotapes and verbatim transcripts of the semi-structured interviews, as well as the field notes and my researcher's self-reflection journal. Data reduction and analysis products and data reconstruction and synthesis products are all intertwined. All these processes were recorded in a detailed chronological account. Finally, instrument development information included the development of the semi-structured interview schedule and field notes. Maintenance of all of these forms of documentation allowed for the establishment of a high quality audit trail.

Triangulation

The purpose of triangulation is to try to gain a fuller understanding of the phenomenon that is under study (Lincoln & Guba, 1985, p. 314). In this investigation, triangulation of data sources was used to deepen the understanding of the phenomenon. The data sources were the participants' transcript-based narratives. Following the establishment of themes, triangulation of data was also carried out by comparing the findings to the results of other studies as recommended by Morse and Richards (2002, p. 179).

Summary of the Study Method

This chapter outlined the methodology components of this phenomenological study. Adult learners attending LBS programs were asked to participate in the study. Fourteen participants were interviewed on two occasions. The data sources were the first and second interviews and interview-based narratives, field notes, and the researcher's journal. Trustworthiness was established through member checks, thick, rich description, an audit trail, and triangulation.

CHAPTER FOUR -FINDINGS

Introduction

This chapter contains the profiles of the participants and the textual description of the patient education experiences using the themes and categories that emerged from the data. It is hoped that the participants' portrayals will help the reader situate the further findings within the context of their lives. Each participant is identified by a pseudonym. Their profiles, developed from their demographic form, are presented below. These profiles have been checked with each of the participants.

There were 14 participants including twelve women and two men. Their ages ranged from 24 to 68 years. Five participants spoke English as their first language and the other participants had a variety of first languages. Two participants spoke Arabic as a first language, two participants spoke Farsi, and two other participants spoke Oromo. Portuguese, Somali, Spanish, and Twi were spoken as first languages by the other four participants. The participants who spoke English as a second language had all immigrated to Canada in the last 30 years. The participant with the longest Canadian residency had immigrated in 1973. The most recent immigrant arrived in 1995. All of the participants were attending LBS classes. All participants were able to discuss their patient education experiences in English.

Similar to many individuals with chronic illnesses, all participants were living with more than one chronic condition. Of the 14 participants, eight had arthritis and five had stomach problems, such as gastric reflux, ulcers, or irritable bowel disease. Four participants had asthma, three had high blood pressure, two had carpal tunnel syndrome, two had diabetes, two had migraines, one participant was living with depression, one had epilepsy, one had a chronic skin condition (Keloids), one had sleep apnea, and one had a thyroid problem.

Participants diagnosed with a mental illness were excluded from the study. One participant that was not excluded from the study, however, did present with mental illness. I did not know that Addie had depression until the middle of the second interview when she began to talk about her psychiatrist. I decided to leave her data in the study due to the fact that she also was living with arthritis and migraines and was interacting with health care professionals for these conditions. She had not seen her psychiatrist in many months.

Participants' Profiles

Abeba

Abeba was 50 years old during the time of the study. She was born in Ethiopia and left in 1991 to join her husband who had been living in Canada since 1988. Abeba and her three children lived in Italy for one year while awaiting their immigration papers, before finally coming to Canada in 1992. Abeba and her family first lived in Edmonton and then moved to this city in 1995. Abeba separated from her husband in 1997. She was living with her daughter and one of her sons at the time of the interviews. Her other son was living in the United States.

Abeba was a friendly, motherly woman, very soft spoken and shy. Her first language was Oromo, but she also spoke Arabic, Somali, Amharic, English, and some French. During health care interactions, she spoke English only.

Abeba was diagnosed with arthritis in 1996 but stated that she had had joint pain since she was living in Italy. She was taking about five or six medications daily for her arthritis. These medications were prescribed to help with pain relief. She saw her family doctor once every three months or so. She mentioned, however, that she might go more often if she experienced problems with her medications. She also saw her arthritis specialist about

once every three months for blood tests. She had to have an eye examination every six months to monitor potential side effects from her arthritis medication.

While in Ethiopia, Abeba completed school to approximately Grade 6 when she was 12 years old. Since her arrival to Canada, she had taken ESL courses as well as a six-month daycare worker course. She had been in the LBS program since September 2001 and had attended the program for three years at the time of the study. Abeba was receiving ODSP income support because of her arthritis. In the past, she volunteered at a daycare for six months but found it was too physically demanding for her due to her arthritis.

Addie

Addie was 53 years old during the time of the study; she grew up in Trenton, Ontario and came to this city in 1982. She had been living with her brother and his wife in an apartment; she found this arrangement difficult. Addie recently had moved to a bachelor apartment. She was living alone and stated that she felt much happier. Addie was quiet but friendly when she got to know you. She spoke English and some French. During health care interactions she spoke English to everyone including her family doctor.

Addie was diagnosed with arthritis in 1972. She also had depression and had had migraines for years. She was on six medications a day; some were for pain relief for her arthritis and migraines, the other medication was to treat her depression. Additionally, she had received cortisone injections to help to decrease her arthritis pain. Addie saw her family doctor about once a month. She also saw her arthritis specialist about once every three months. Addie had seen a psychiatrist off and on for years. She was not seeing her psychiatrist on a regular basis at the time of the study.

Addie completed Grade 8 when she was 13 years old. In 1992, she went back to school for one year to complete a high school equivalence course and obtained her high

school diploma. She had been in the LBS program since September 2003 and had attended for eight months. Addie had worked as a security guard in government buildings in the past. She received financial support from the Ontario Works program and at the time of the study, was awaiting approval for ODSP income support due to her arthritis.

Carolyn

Carolyn was 25 years old during the time of the study. She was born in Calgary, Alberta and spoke English as her only language. Her family moved to this city when she was four years old. Carolyn was a single mother who lived with her four year old son in an apartment. Carolyn was a very outgoing, friendly young woman. She laughed easily and was very open to discuss her chronic illnesses. Carolyn was diagnosed with a thyroid condition in 2002 and was also diagnosed with carpal tunnel syndrome in the same year. She was on one medication that she took daily for her thyroid problem. Carolyn also had splints that she used at night for her carpal tunnel syndrome. She saw her family doctor about once every three months.

Carolyn left high school when she was 19 years old because she was pregnant. At that time she had completed Grade 10. Carolyn had been in the LBS program since September 2001. She had attended classes for two and a half years and withdrew from class during the study to work full-time as a cashier in a store. She had been working part time at night as a cashier while attending the LBS program but found that she did not have enough money for her family's living expenses. While in high school, Carolyn volunteered with children who had autism; she found she was very relaxed around the children and really enjoyed the experience. Because of that experience, Carolyn was planning to attend a community college in a government sponsored program for youth and childcare workers in the following year.

Louise

Louise was 58 years old during the time of the study and was originally from Nova Scotia. She moved to this city in 1990 by herself and lived alone in an apartment at the time of the study. She had three children and five grandchildren. Her daughter lived in this city; her other children lived throughout Canada. Louise seemed to require time to open up to get to know people. Louise used her only language, English, during all her health care interactions.

Louise was diagnosed with high blood pressure in 1999 and arthritis in 1994. The arthritis affected mostly her back and knees. Louise also had a stomach ulcer and found it difficult to take pills. She was taking one pill a day for her high blood pressure and also some herbal medication for symptoms related to menopause. She saw her family doctor about five times a year, once every few months. Louise mentioned that she came from a large extended family and that she had brothers and a sister who also had high blood pressure.

Louise completed Grade 7 in Nova Scotia when she was 12 years old. Louise's discontinuation of school was related to the death of her parents. Her mother died when Louise was seven years old and her father died when she was 11. Louise did not speak until she was six or seven years old, and did not attend school until that point. Following the death of both her parents, Louise's stepmother looked after her for awhile. However, her stepmother was physically abusive and Louise left home at 13 and began working as a housekeeper. She had been in the LBS program since September 2000 and had attended for three and a half years. Louise had also been working as a cook in a retirement home for approximately eight years.

Lynn

Lynn was 34 years old during the time of the study. She was originally from Ghana and arrived in Canada in 1991 by herself. She first lived in Montreal until 3 years ago when she moved to this city. She was a single mother who was living with her two children, a four year old son and a two year old daughter. Her son had been diagnosed with a speech problem (stuttering). She spoke Twi, English, and some French. While she was in Montreal, her family doctor, who was also originally from Ghana, spoke Twi, so they spoke Twi together. Lynn was not able to find a doctor that spoke Twi in this city. Lynn therefore spoke English during all her health care interactions.

In 1995 Lynn was diagnosed with Keloids, a chronic skin condition. She had been treated with multiple injections, ultraviolet light, and had two surgeries. She was not on any prescription medication but had been advised to use a Vitamin E cream daily to treat her skin condition. She had seen her family doctor in Montreal one to two times a month. Lynn does not like her family doctor in this city and does not visit with him anymore.

Lynn completed Grade 10 in Ghana approximately 24 years ago. Since her arrival in Canada, she had taken ESL courses and had been in the LBS program since September 2003 and attended for eight months. She was volunteering at a women's shelter in the city where she helped prepare meals and talked with the women.

Mekal

Mekal was 50 years old during the time of the study. He was originally from Brantford, Ontario. He came to the city in 2002 with his wife and son because his wife received a job transfer. He lived with his wife and 16 year old son in a house. At the time of the interview, Mekal was building his family a new house with the help of some friends. He was an outgoing, fun loving man, and a leader in the classroom. Mekal was very self-assured

and readily spoke of his life goals. He spoke English and a bit of the First Nations language of Cree. Mekal spoke English during health care interactions.

Mekal was diagnosed with arthritis when he was approximately 16 years old. He also had gastric reflux from time to time. He was on six medications a day, including pain and sleeping medications and a water pill. He saw his family doctor about once every three months. Mekal mentioned that once or twice a year his arthritis pain was too severe for his regular medications to control; in these situations he visited the emergency department at the local hospital for stronger pain medications.

Mekal left home when he was only 13 years old because he did not get along with his father. He also left school at that time, having only completed Grade 3. He ended up working in a variety of jobs that took him all over North America, from Florida to the Northwest Territories. He had been in the LBS program since January 2003 and had attended for 16 months. Mekal had volunteered in the past with a Cree First Nation group by setting up a computer system in a school. In the future, he would like to take computer technology courses at a local community college.

Monique

Monique was 52 years old during the time of the study. She was originally from New Brunswick and moved to this city in 2001. She lived with her second husband in an apartment. Her husband also had some health problems. She had a son, who also lived in the city. Monique's son recently had his own son, so Monique was a grandmother for the first time and very excited about this new part of her life. Monique was friendly and outgoing. She spoke French and English and only English during health care interactions.

Monique was diagnosed with epilepsy when she was 22 years old. She had been on medication for her epilepsy ever since her diagnosis. Monique felt that she had had asthma

all her life but was not diagnosed until her son was born in 1980. She also had gastric reflux for many years. In 2002, she was also diagnosed with osteoarthritis. On average, she saw her family doctor once a month to once every two months. She was on four medications a day for her epilepsy, asthma, and gastric reflux disease.

Monique completed Grade 8 when she was 20 years old. She missed a lot of school when she was younger due to illness. In retrospect, Monique thought that she may have missed school due to her asthma. She had been in the LBS program since September 2003 and had attended for eight months. Monique volunteered at her church once a week and once in awhile at a drop in centre for street people where she would help by giving out meals. She wanted to continue school and had thoughts of becoming a nurse when she was younger. At the time of the interview, Monique thought she would like to become an interpreter for people using sign language.

Nasreen

Nasreen was 69 years old during the time of the study. She was originally from Iran and arrived in Canada in 1974 with her husband and two children. She lived with her husband, her two sons, a daughter-in-law, and two grandchildren. Nasreen was the oldest participant in the study. She was very loving, caring, and somewhat soft spoken. Nasreen spoke Farsi, English, and a bit of Arabic. Nasreen spoke English during health care interactions.

Nasreen was diagnosed with arthritis 10 years ago, diabetes six years ago, high blood pressure four years ago, and asthma two years ago. She saw her family doctor about twice a month. She was on approximately four to six medications daily including painkillers, anti-inflammatories for her arthritis, and medications for her diabetes and high blood pressure. Nasreen was using an inhaler for her asthma.

Nasreen left school in Grade 11 in Iran when she was 19 years old. Since her arrival to Canada, she felt that she had not been able to take courses due to the time constraints of raising her children and working. She had attended the LBS program since September 2001 for two and a half years and left the program when her mother became sick at the end of December 2003. Nasreen had been on ODSP income support for a number of years until she turned 65 when she then began receiving the Federal Old Age pension.

Nigist

Nigist was 41 years old during the time of the study. She was originally from Ethiopia and arrived in Canada in 1994 with her husband and her seven children. They settled in this city and her husband died of cancer two years later in 1996. He had been diagnosed three months earlier and had spent those three months in the hospital. Her children ranged in age from 9 to 26 years old. Her two oldest children lived with her sister in the city and the other five lived with Nigist in a house. Nigist was a very fun loving woman who had had to deal with incredible adversity including the death of her husband. She had dealt with these hardships by thinking that everyone had difficulty in their lives. She spoke Oromo, Amharic, and English. Nigist spoke English, during health care interactions.

Nigist was diagnosed with an ulcer in 1996 following the death of her husband. She was diagnosed with arthritis in 2002 and saw her doctor about once every three months and visited him more often in the winter months. One of her daughters (the 15 year old) had diabetes since the age of four. Nigist was on one medication for her ulcer and one for her arthritis.

Nigist completed eight years of school in Ethiopia and was 11 years old when she left school. Since her arrival to Canada, she had completed a six-month home support worker course and had worked with a centre which offered health and social services to residents of

an area in the city. She had been in the LBS program since September 2002 and had attended for two years. Nigist had to leave the program because she experienced a lot of pain when she was sitting in class. She planned on going back to school in the fall once she had more tests to find out what was causing her increased back pain.

Nyela

Nyela was 40 years old during the time of the study. She was originally from Somalia and arrived in Canada in 1995 with her children. Her husband had been in Canada since 1989 and was their sponsor. When Nyela arrived in Canada, her family lived in Toronto and moved to this city in 1999. Nyela lived with her husband in a house with five of her seven children. Her children ranged in age from 5 to 23 years old. Nyela was an outgoing and friendly woman. She spoke Somali, English, and a little bit of Arabic; during health care interactions she spoke English.

Nyela was diagnosed with high blood pressure in 1990 and diabetes in 1998. She was on nine medications a day, approximately eight for her diabetes and one for her high blood pressure. Because of her diabetes, she also took her blood glucose level daily. She saw her family doctor approximately once a month to once every three months. She had to go for blood tests at a lab every three months.

Nyela completed high school in Somalia in 1985. She began the ESL program in 2000 and started attending the LBS program in September 2003; she had attended this program for eight months. Nyela worked evenings cleaning offices.

Ramon

Ramon was 41 years old during the time of the study. He was originally from the Dominican Republic and arrived in Canada in 1990. Ramon was sponsored by his girlfriend. Since their break-up, he was living with a roommate in an apartment. Ramon was quite soft

spoken and spoke Spanish and English. He spoke Spanish to his family doctor and English during other health care interactions.

Ramon was diagnosed with chronic pain in 1994 after being in a car accident which resulted in a back injury. He had received physiotherapy for his injury. In 1999 he was diagnosed with sleep apnea and was using a CPAP (continuous positive airway pressure) mask machine to help him sleep at night. He saw his family doctor one or two times a year for physical examinations. Ramon would go to a walk-in clinic for any other health-related problems. He saw a chiropractor about once a month for his pain. He was not on any prescription medications but did use over the counter pain medication when the pain was too much to bear. He found that sometimes the medication had an effect on his breathing so he had to be careful.

Ramon completed Grade 12 in the Dominican Republic in 1982. Since his arrival in Canada, he had taken ESL courses and had attended the LBS program for three years since September 2001. Before his car accident, Ramon had cleaned offices and also worked as a security guard in an office building. He had been receiving ODSP income support since 1999.

Sonia

Sonia was 34 years old during the time of the study. She was originally from the Azores Islands in the North Atlantic. Sonia arrived in Canada in 1988 by herself to join her sisters who were already living in Canada and were her sponsors. Sonia lived with her 9 year old son in an apartment. Her son had asthma and recently had pneumonia and needed to be hospitalized overnight. Sonia was full of energy and spoke both Portuguese and English. She spoke Portuguese with her family doctor and English during all other health care interactions.

Sonia was diagnosed with asthma as an infant, when she was approximately six months old. She used two medications, her “puffers,” each day for her asthma. She saw her family doctor in the winter approximately every two months and in the summer every three to four months. Her asthma would usually worsen around Christmas, so Sonia had to see her family doctor more often at that time of the year for antibiotics. One of Sonia’s sisters also had asthma. Sonia also had tendonitis in her elbows and had some back pain. She saw a physiotherapist and was possibly going to have surgery for her tendonitis in the following few months.

Sonia completed seven years of school in Portugal (from age 7 to 14). Since her arrival to Canada, she had taken ESL courses and had attended the LBS program for three years since September 2001. Sonia began working for a dry cleaning business as soon as she was able upon arriving in Canada. At the time of the study, Sonia was part of the Ontario Works program. Sonia was thinking of taking a course in Toronto that would train her to work in funeral homes as an assistant to the mortician.

Sophia

Sophia was 53 years old during the time of the study and was originally from Syria. She arrived in Canada via Iraq in 1991 with her mother. Sophia’s brothers, who were already in Canada, sponsored them. Sophia took care of her mother after arriving in Canada. Both her mother and one of her brothers died in 2001. Sophia was living with her other brother in an apartment. She was a quiet, shy woman, who at times appeared nervous. Her life had been difficult. She was a very soft spoken woman and spoke Armenian, Arabic, Turkish, and English. She spoke Arabic to her family doctor and English during interactions with other health professionals.

Sophia was diagnosed with breast cancer in 2000 and had surgery to remove her breast shortly after her diagnosis. She was also diagnosed with osteoporosis in 2000 and asthma in 2002. Sophia had difficulty sleeping after the sudden loss of her brother and mother within one week of each other in August of 2001. She was usually on medication for anxiety and pain and was awaiting test results to determine if she needed heart medication. Her doctor was cautious about giving her medication due to her history of cancer. She saw her family doctor two to three times a month to once every three months. Every couple of years Sophia had a bone density exam.

Sophia completed Grade 7 in Syria when she was 13 years old. She took ESL courses at Algonquin College for four months when she first arrived in Canada in 1991. She began the LBS program in 2002 and had attended for almost two years. Sophia had never worked outside the home.

Warda

Warda was 45 years old during the time of the study. She was originally from Lebanon and arrived in Canada in 1979 with her husband. At the time of the study she lived with her husband and four children; a 24 year old son, a 23 year old son, a 19 year old daughter, and a 16 year old son. She was a strong, independent, friendly, outgoing, and an opinionated woman. She spoke Arabic, English, and a bit of French. Warda spoke English during health care interactions. She had also spoken Arabic with her gynecologist before he retired.

Warda was diagnosed with migraines approximately 20 years ago, arthritis in 2000, irritable bowel syndrome in 2001, and carpal tunnel and tennis elbow in 2002. She did not like to go to doctors, but she did go when she was in pain, which was probably a few times a year. She saw different doctors including her family doctor and an arthritis specialist. She

was on a number of medications including pain killers, anti-inflammatories for her arthritis, medication to decrease her cholesterol, and medication to increase her calcium level.

Warda completed her first year of high school in Lebanon (approximately Grade 11 in Canada) when she was 18 years old. Since her arrival to Canada, she had not been able to take courses due to time constraints associated with raising her children and working. She had been in the LBS program since September 2003 and had attended for eight months. Warda worked as a hairdresser on weekends.

In summary, the participants represented a cross section of the different people who are living with limited literacy and chronic illnesses. They had lived with chronic illnesses from one to 34 years of age with an average of nine years. Some participants were born in Canada while other participants were born in other countries and later settled in Canada. They ranged in age from 25 to 69 years and were comprised of two males and 12 females. Some participants lived with families, others lived alone. Some participants had young children, some had grown children, and other participants had no children. Some of the participants had had previous schooling of only a few years to one participant having completed high school in her country of origin. All of the participants had experiences with patient education and there were some common themes that emerged which will be discussed in the next section.

Patient Education through the Eyes of the Participant

As with most qualitative research, this study has uncovered an abundance of rich data. This section will present the textual description of the findings divided into the main themes and categories that emerged from the data. Categories represent the elements or meaning units that evolved from the significant statements of the participants' transcripts. They reflect the particular aspects of the experience. Themes emerged from these categories

which represent the different components of the experiences. According to van Manen (1997b), the theme is a tool for getting at the meaning of the experience.

The five themes that emerged from the data are different roles and relationships, language and health care interactions, living between worlds, mismatched expectations and powerlessness. These themes help to describe the nature of the patient education experiences for the participants. Quotations will provide an opportunity to hear the rich, insightful, illuminating voices of the participants.

Different Roles and Relationships

Participants interacted with a number of different people during their patient education experiences and people played different roles within these relationships. This theme captures the different functions that people assume. As well, this theme also highlights the number of diverse interactions that participants have as a result of patient education experiences. Within this theme are the categories of the role of health care professionals, including the role of doctors, nurses, and pharmacists. Participants' family members take on roles of helper, translator, mediator, interpreter, and the role of accompanier in helping them navigate through the health care system. Finally, the perceived role and responsibilities of the participants in their own care is discussed.

Role of the Health Care Professionals

The different roles of health care professionals as perceived by the participants, included educator, advisor, and provider of health care treatment. All of the participants felt that the role of the doctor or other health care professional was to inform them about their condition, give them information about their chronic illness, and treat them for their chronic illness. The health care professional should “advise or educate patients,” as Mekal put it,

about what to do and not to do to make the condition worse. Mekal thought that the health care professional should

inform me that I have it, and treatment for it, okay, that's how I see his role, to inform you to say okay you have arthritis, this is what arthritis is and these are the things we can do to. If it is going to hinder or worsen, he is supposed to inform me that you know some of the routines that I am doing, that I shouldn't be doing, limited myself to you know half an hour a day exercise, umm, the distance I walk. These types of things he should be informing me about things like that.

Lynn also stated that the role of the health care professional was to tell the patient what they should do about their illness and also how to treat the patient's illness, to “help me to understand so that I can help myself.”

All the participants mentioned that the majority of health advice and information that they received about their chronic illness came from their family doctor and their pharmacist. The doctors and pharmacist were seen as facilitators to help participants increase their knowledge. The participants also talked to nurses and specialists about their chronic illnesses. They saw all these health care professionals in the role of educator.

Participants realized that they needed their doctor's help to understand their condition. Carolyn felt that the role of the doctor was to try to get the patient to understand about their conditions, not just give them medication. “He should help me, educate me, as much as he can at that time.”

The other key health care professionals that all the participants interacted with were pharmacists. All the participants were on at least one medication that had been prescribed by their family doctor to help manage their chronic illness. The participants were advised to use the prescribed medications on a daily basis. Many participants also used over the counter

medication including herbal products. The medications ranged from the use of a daily topical cream for one of the participants, to taking nine different prescribed medications per day for another participant. The participants got their prescription medications through a pharmacy where they interacted with pharmacists.

All participants stated that they did not mind or worry about asking questions to the pharmacist. The participants felt comfortable, trusted the pharmacist, and stated that it was easy to talk to them about their chronic illnesses at the pharmacy. The participants knew that the pharmacist needed to know information about their condition so that he or she could help them. Sonia talked to her pharmacist as well as her family doctor about her medication because

they know you take this medicine so all the time they give you a review of it, they talk a lot about it and the pharmacist do that all the time. You are not just going to walk away from them, you are going to pay attention to it, and okay sometimes you say ya, I know and sometime you hear something different and I am going to try that.

Abeba actually used her pharmacist somewhat like a mediator for what the doctor talked to her about. She found, at times, that the doctor spoke too quickly, so she would ask the pharmacist to explain. She told him “that her English is poor, that they need to speak slowly and to repeat information, and then she asks him to write the information down.” She found this strategy very helpful and she felt that she could trust the pharmacist.

Ramon noted that people talk to their doctor about their health and not other people in health care because “they probably think that only the doctor, he, they have the answer for them” and that “patients think that other health care people don't know as much as the doctor knows.” Participants perceived that the role and responsibilities of nurses in patient education experiences to be somewhat different than that of physicians. Abeba stated that she

would talk to the nurses when she felt that the doctor did not have enough time. She saw the nurses' role as helping the doctor. The nurse would give the doctor information about the patient, but the nurse could not make a decision about the plan of care. That was the role of the doctor according to Abeba. Mekal felt that the nurses were not as qualified as the doctors, because "they have not been to school to learn everything that the doctor has." He felt that they would not be able to make a decision. The final decision would be up to the doctor. This is similar to Warda and Louise's opinions about the nurses' roles and knowledge base.

The health context of this study was that participants were living in a large urban centre which had the availability of medical specialists that were experts in treating the different chronic illnesses of the participants. Many participants had seen a specialist to have their chronic illness diagnosed. In fact, Mekal mentioned that he was sent to several specialists "to make sure what they say it is." Once his diagnosis was confirmed as arthritis, he was sent back to his family doctor. He had not gone back to the specialist since his diagnosis. In the case of Abeba, she found that going to the specialist actually helped her to understand about her arthritis. When her doctor first told her about arthritis, she thought it was "tired bones" and did not really understand about the condition. Abeba stated that it wasn't until the specialist told that her "arthritis wasn't bad but it would not go away but it would be helped by taking pills." Abeba was not sure why hearing her specialist tell her this information made a difference in her understanding, but it did. Abeba indicated that both her family doctor and specialist were very good at explaining things because they were very nice and would talk slowly and laugh. Such behaviours made Abeba feel comfortable and unafraid to talk to them.

The only other health care professionals that had treated the participants for aspects of their chronic illnesses were physiotherapists and chiropractors. Ramon and Sophia had

seen physiotherapists for a short period for their conditions. In addition, Ramon and Addie had seen chiropractors. These health care professionals also had roles of educator, advisor and provider of care. Sophia received treatment from a physiotherapist following her mastectomy due to her breast cancer. Ramon had seen a physiotherapist after his car accident, when he attended a group session on pain management techniques. He remembered that the physiotherapist used to tell him:

whatever you think you are normal you are not normal. You have to understand that, that has to do with the pain. Like normal in the world like a human being like normal like you, and everybody the pain is not the same. It is not normal like a person who doesn't have pain.

Addie had seen a chiropractor to help relieve pain from her migraine headaches. She found the treatment helpful and said that the chiropractor was “very good with me, they explain, they explain pretty well in detail with me and they help me a great deal.” Ramon saw his chiropractor monthly which he felt helped his chronic pain.

Some of the participants also had used the services of complementary or alternative health care practitioners. Louise mentioned that she went to the health food store to get some herbal medicines and would talk to “the ladies there and ask for their help to make sure that the herbal medicines will not interfere with her high blood pressure.” Louise also saw someone for acupuncture who had recommended that she try Promensil instead of Estrogen for her menopause symptoms. Addie indicated that “years ago I went to see a naturopath by myself after seeing a show on the health channel.” The naturopath appeared to help her by recommending that she try herbal medicines for her pain. Again these health care providers had roles of educator, advisor, and provider of care.

Roles and Relationships of Family

Living with limited literacy and a chronic illness not only affected the lives of the participants, but also the lives of their families including their spouses and their children. Most participants relied heavily on family members to attend doctor's appointments with them or provide explanations when they returned home. They also asked their family members to help them fill out forms, look up health information on the Internet, and pick up medication at the pharmacy. The participants' family members had roles of accompanier, advisor, and mediator.

All participants who had spouses talked to them about their health issues. The participants also had their spouses accompany them to their health appointments. Warda and Mekal both mentioned that they would bring their spouses to appointments "simply as support." Nyela, at times, would have her husband attend health care appointments, but since she returned to school, she understood more and therefore felt comfortable to attend her appointments by herself. Monique and her husband would plan their appointments so that they were together when they talked to the doctor, because Monique "likes to know what is going on" and this way she felt that she and her husband could learn about each other's conditions. Monique's husband also lived with chronic illnesses: epilepsy and hepatitis C. Monique mentioned that her husband also had difficulties with literacy. Monique felt that she had stronger literacy skills than her husband. Monique stated, "I am the one to do the bills and everything because my husband is illiterate I am the one doing everything." At the time of the study, her husband was planning on learning how to read and write with a one-on-one tutor.

A few participants had someone in their family who also had the same chronic illness and this person was used as an advisor. Nyela spoke with her family about her diabetes and

received diet-related advice from her uncle who also had diabetes and who lived in Somalia. He told her “not to make the cakes” so she would not be tempted to eat them. Nyela found that hard to do, because her children enjoyed the cakes, but she did try to follow his advice. She felt that he knew about these issues because he had lived with diabetes for a longer time than she had.

Sonia’s son and her sister also had asthma. Sonia talked to her sister a lot about her asthma. Her sister's asthma was a little bit worse than Sonia’s; her sister went to her specialist about once a week. Carolyn found it helpful that her father also had carpal tunnel syndrome. This allowed her to learn from his experiences and enabled her to ask him for ways to deal with her own health problem.

I am lucky with the carpal tunnel, I was able to ask my dad because he has gone through it, he has had surgery once, once on each wrist. He's gone through everything that I'm about to you know, the experience, or it might be a bit easier for me. However, having a family member with the same chronic illness was not always helpful to the participants. In Lynn’s case, she spoke with her father about her skin problem but he thinks that is it nothing to be worried. That's what he thinks, because I went home [Ghana] 5 years ago because of this, it bothering me, I went home because of this. I had heard of people, they have a local herbalist, herbal, they do have it to treat but unfortunately, when I went because he thinks it is nothing to bother, he didn't take care of me.

Other important members of the participants’ families were their children, who took on different roles and responsibilities for their parent. Nigist would take one of her seven children to her appointment with her, whoever did not have school or work that day. Her 23 or 26 year old children would usually go with her but sometimes her 15-year-old daughter

accompanied her to her appointments. Regardless of which child Nigist took with her to her appointment, she stated that she liked having one of her children with her, so that her child could help her understand exactly what was going on with her health.

Another role that the children took on is one of a mediator for health information that the participants received. Participants asked their children to explain terms or words that the doctor used or that the participants had written down either during or after their appointment. Some of the participants stated that when they received patient education material, such as pamphlets, and they could not read them, that they took these pamphlets home so their children could help them read the material. Abeba stated that she had asked the doctor to write out words that she did not understand and then took the paper home to show her children and they told her what the word meant. In another case, Louise used her daughter's health knowledge to help her condition. Louise mentioned that she would speak with her daughter and asked her questions about what she should eat to help her arthritis and high blood pressure since her daughter studied nutrition at school.

The roles that the children took on as advisor, educator, mediator, and accompanier could result in the child taking on a more traditional parental role. This resulted in a role reversal in which the child was more knowledgeable and the parent took advice from the child. Their families were aware of the participants' limited literacy and acted in different roles to support the participants in their literacy activities, such as filling out health forms and reading patient education pamphlets. These activities appeared to help the participants in improving their health and their personal well-being. All of the participants mentioned that as their literacy abilities improved due to going back to school, they were able to take on more of these roles by themselves and that they didn't need to rely on their family members as much.

Self Responsibility for Health

For the most part, participants felt that they had an important role and a responsibility for their own health. Participants acknowledged the need to take on an active role in taking care of their own health. The participants realized that they needed to get information about how to deal with their health problems. Monique stated, “I want to know what to do with my own health.”

As Abeba noted, “you are responsible for your own health and I’ll always say a doctor is a doctor but a doctor is not God, so you got to have, do it for yourself.” Most participants mentioned that they really knew what worked and what didn’t work for their bodies, since they lived with their condition for years. Sophia knew that she could not control everything about her health but she could control and be responsible for some aspects of her health. She tried to control her body and knew “what works with me, for that, until now I know how control my self, you know I can’t control the cancer, the osteoporosis these are different things.” The participants felt that the doctor helped them gain a better understanding, but it was still up to them whether or not they would change their behaviour. For example, the participants believed that some of the medications that they were prescribed were not that helpful in treating their chronic illness. Sophia mentioned that if the medication did not make a difference in her symptoms after taking one or two pills, she would stop taking them. Sophia wanted to

listen to my body, I don't listen to myself too, I listen to my body and what it says to do. I do not like sometime I take medication they give me, I took a few capsules, or tablets or whatever when I feel that I am feeling better, like that it means works I continue. If I take a few and it didn't help it's not going to help me, because I tried many times so, I know my body what it accepts or not accepts.

Louise believed that she was responsible for her own health and for getting information about how to deal with her health problems.

Sonia thought that if the patient understood their illness, they could take on more responsibility for his or her health:

the doctor is not going to be there with you, his advice, his information, and his prescription to you it's up to go to look after that. He can not run and go to you to your house. People that have a sickness, especially if they have had it all their life they have to be aware, they have to look after themselves, nobody else will do it for them. When you are a child you have your parents to help you out, otherwise you know, it's a cross, it's like having a leg, you have to carry your leg everywhere you go. So it is up to you to know if it is cold or hot outside your brain has to do these things for you, you don't have the doctor all the time to say, oh you have to, you're coughing too much you should take the syrup, no you take care of yourself.

Addie stated that she felt that she wanted to know about her arthritis to control it. She felt that if you have information you “know what bothers you and approximately what is going on with your body.” Carolyn felt that she should do her part to obtain information by asking her doctor questions. Carolyn felt a greater level of confidence to ask questions upon her return to school. Sophia wanted to know as much as she could to help. She said:

I want to know about everything, like if you interested maybe if you don't have a problem you don't care, but when you have a problem you have to follow some information to know and maybe some people like they don't have osteoporosis. They say I don't care why I have to listen but when I have I want to know more, what I have to do and what, what will it cost for future, what is going to do it to me, how I take care of it, so what I have to, yes I want to know about.

These comments are similar to those of Nigist, who always looked for health information through the Internet and television programs. Warda hoped that she would learn how to use the computer at school, “how to look health things up in the computer.” Addie started to use the computer at school and had looked up health-related information, such as how to deal with arthritis. Monique knew how to use the computer and had used it to search for information about sleep apnea for her mom, but she “can't find nothing, nothing, I found something but is not enough for info.”

Summary of Different Roles and Relationships

Participants were involved in a number of different relationships, and in these relationships people played different roles. Both health care professionals and family members took on the role of an educator and advisor for the participants; to help them with their chronic illnesses. Family members also took on the roles of accompanier and mediator, helping the participants deal with limited literacy and their chronic illnesses. Finally, this theme included the roles that the participants took on to help themselves to understand and manage their own chronic illnesses.

Language and Health Care Interactions

Not surprisingly, given that the topic of this research was in the area of literacy and health, language and health care interactions emerged as a theme. This theme represents the different aspects of the use of language; the actual discourse in patient education experiences. Within this theme are the categories of verbal and written information, vocabulary, and English as a second language.

Verbal and Written Information

All of the participants had received patient education both verbally as well as in a written format, such as pamphlets. Because of the long-term aspect of their health problems,

participants interacted with their health care providers for a number of months or even years. Therefore, participants had many different types of verbal interactions with their family doctor. Sometimes these interactions were not pleasant for the participants. Warda noted that it depended on the health care provider:

Ya sure, some doctors, you feel comfortable to some doctor. They doesn't like, they doesn't speak too much, you pull the word out of their mouth you know, some they ask you, thing you know, you want, you know about it but you want maybe shy to ask, you forgot sometime, it's different, each doctor is different, you know.

When asked if they thought about what they wanted to talk to the doctor about before going to see him or her, the majority of participants mentioned that they thought about what questions they had. When asked if they wrote these questions down, only two noted that they did; Sonia and Addie. The others responded that they had excellent memories and did not need to write things down, but also mentioned that they often forgot to have their questions answered by the health care professional because of time, going off topic, or other issues.

Participants found that it was helpful when their family doctor used pictures, props, and other models in his or her office to explain things. Ramon thought that health care professionals should use pictures and models like skeletons. They need to not just talk “about it, they need to show what it is, and go to the bottom of and then show the injury so the patient can understand better that way.” Mekal mentioned that such props often were not used, even when they were physically present in the doctor’s office.

In terms of written patient education material, a few of the participants found the information useful. Many participants expressed that they did not keep the pamphlets so that they could refer back to them. They felt this was unnecessary since once they read the

document, they knew the information. As well, almost all of the participants indicated that they received so much written information in general, that they found that the patient education material was just more paper to be discarded. In contrast, Addie kept a detailed folder with all her medication information so that it remained readily available. The pharmacist had complimented her on how organised she was with her folder.

Sonia would “carry the pamphlet that he gives me, like he usually gives me something about what you have and I usually read it over and over at home.” Carolyn reported that she really did not feel she needed written information because her doctor or pharmacist’s verbal instructions allowed her to understand what she should do. However, she also stated that she kept written information about her medications. Carolyn mentioned that she kept the medication pamphlets to allow her to consult the information regarding potential side effects:

If it is a new medication like for me. I will keep it for a little bit [the information from the pharmacist] because of symptoms and if you are having a reaction and things for my son. If he is on any medication I try to keep [the information from the pharmacist], a little while so you know, I would understand what is going on and if it is normal or not.

To make written patient education more helpful and interesting, Mekal recommended pictures as well as an increased use of colour, because “if it is all words, it is boring.” He also thought that the pictures used on medication bottles to alert patients to possible side effects or to instruct them on proper use, such as whether one should take the medication with food or on an empty stomach, were very helpful. He felt that if pictures were used more “that the person would understand a bit quicker than anything else.”

Vocabulary

Vocabulary played a key role in health care interactions for the participants. All the participants noted that they understood the majority of what the doctor talked to them about. At times, however, they did not understand some of the words that the doctor used. Warda felt that she understood everything that her family doctor talked to her about. If she did not understand, she would ask for clarification, “like some word I don't understand, especially in medical, I don't understand all the words they are talking about. I said what is that supposed to mean, please, he show me sometime, like a diagram.” Sonia felt comfortable to ask questions to make sure she understood. If she didn't understand what a word was, she would ask what it meant:

If they go like through words like pulmonary and stuff like that, if it is like a medical word, it's difficult, but then I ask them what it is, but it is actually not very important as long as they explain to you it is the tubes that go to the lungs.

Sophia found it relatively easy to fill out forms and get around the hospital because people helped her “they give me like an easy word, so I understand them, or they if I don't understand the word exactly what it is they explain it to me so by that they see me, I understand what they say.”

Carolyn also discussed the issue of vocabulary during doctor's appointments. She stated that she understood the majority of what the doctor talked to her about. If she didn't understand, she would ask him questions; “he breaks it down for me, I'm not shy like that, cause in my head I think well I'm not a doctor.” This was similar to comments made by Louise, she found that her “doctor she's been trying to help me but, she is a very good doctor, but it's a lot of things that you don't understand, like the big words they use.” Louise thought

that the doctors should instead “break it down for you but they don't break it down the way it should be.” Louise found that she understood more words since she returned to school.

Mekal felt that he should know some of the medical terms that the doctor used when she talked to him about investigations to look at his arthritis because “the doctors can't put things in layman's terms. They are not use to it I guess, they are use to their mumbo, jumbo.” This is not just a reflection on the vocabulary, but the actual discourse used in medicine.

English as a Second Language

Within this study, the participants had to deal with vocabulary that was difficult for them. As well, some of the participants also dealt with English as a second language during their health care interactions. None of the participants expressed that it mattered what language their family doctor spoke, as long as the doctor was nice and kind and that they felt comfortable with the person. Abeba mentioned that it actually wouldn't be better if her doctor spoke her first language because “how do I learn English.”

Mekal, whose first language is English, commented that he thought it might be “severe” for people in his class that didn't speak English to receive health information because of the large words, people talking too quickly, new vocabulary, embarrassment, and fear of asking questions. Nasreen also mentioned that she thought that receiving health information was difficult for people who do not speak English well because “they don't understand the language the way it should be” they could “grab the word and it is wrong.” She thought that this could lead to people actually getting hurt because they misinterpreted what the word meant. The participants who did not have English as a first language did not feel this way. They did not appear to be intimidated by the doctors. All participants stated that they felt comfortable to ask questions. Warda stated that she would certainly ask questions and if she did not understand things she would say to the doctor, “can you please

explain more for me.” Warda wanted to know what was going on because her health was very important.

Lynn did acknowledge that it was harder to deal in her second language during health care interactions.

Some doctors or nurses they talk maybe faster and they should know that people don't speak English. English is their second language, so they have to translate to whatever their language to before the English so it would take time for them to understand because you have to think two times before you can understand so, so I think people should give a time to ask are you understanding, go slowly and not big words, not like doctors have a big words, like just coming down. Instead of using terms, doctor's terms, use normal terms.

Lynn found, however, that since she returned to school, that she was able to understand more. Abeba would tell her doctor if she didn't understand a word and would ask the doctor, for example, to write down the word for a name of a medication. Abeba would tell her doctor that she was going to show the word to her children and would talk to them about it.

Sophia knew that she must learn English because everyone in health care, except her family doctor who spoke Arabic, spoke English, so “I need to learn lots of words to communicate with them and they communicate with me.” Sophia expressed, however, that health care professionals need to be patient because it was not her fault that she didn't understand English as well as other people.

Nigist also commented that she thought that receiving health information “is difficult” for people who do not speak English. Nigist had a terrible experience when she first came to Canada, which she believed was because she did not know English.

One time I went to the clinic, not my doctor, another clinic because I don't know this

doctor and then we are new here and I don't speak English, a little bit French, a little bit English, so at that time I have pain, I went to the clinic and the doctor he checks and he says 'You have to go right away to the hospital', I was, I don't know, I said 'Why doctor?' he said 'You have appendix we don't have time we have to do operation now', so I don't know where is the Queensway what he said, I don't know even the bus, I don't know the street I ask the bus, 'Which bus go to Queensway?', I didn't call my house, I didn't call my husband or my kids, I went to the Queensway hospital somebody show me and then I went over there, the doctor he check me he was in operation room so when I went to information I gave them the paper, 'Where is your doctor, who is your emergency contact?' and so when they ask me this thing, I say, "Oh I'm going to die", Why you are asking me an emergency contact? They said 'Oh we have to ask everything' Oh, today I'm going to die, then when the doctor he finishes his operation, I was, my heart beat, maybe I don't know and then the doctor he call me, he say 'What happen to you?', I gave him the letter, I don't know the doctor send me, he said 'Okay', he take me in the room, a type like this, who tell that you have an appendix, I said 'The doctor he write', he said 'Don't worry you're okay, you're 100 percent you don't have an appendix or anything, just you have a little bit cold, you don't know the cold, go home'. I was very happy. Still when I went home I cried, because do you know why I cried how I don't know English, how I don't know where I go, that's why

From then on Nigist has always asked her doctor if she did not understand. As stated by Nigist:

every time if I don't understand I ask him again 'oh, what do you mean doctor? I

don't understand' and some times I ask him, if this subject it is strong, will you write me the word and what this means and I ask and he give me the name and I come home and I ask my kids the translation for me, yay, it is really good, ya ya.

Nigist believed that people in her situation could be helped with a video or a translator. She thought that the translator could be a family member, a close friend, a nurse, a coordinator at the hospital, anyone that the patient could trust. Warda, having lived in Canada for over 25 years, and having interacted with the health care system both as a patient as well as a mother taking her children to appointments suggested:

well, if they can you know, it is hard to get a translator you know in each office to translate different language. But ahh, if they can ask the patient to bring somebody with them that speaks the language. They can translate for them. That's the most easy way for the doctor and the patient to understand each other you know.

Summary of Language and Health Care Interactions

The theme of language and health care interactions revealed the significant role that language plays for participants in different health care interactions. Within this theme were the categories of the two main delivery channels of patient education; verbal and written information. Both methods of patient education delivery can be a challenge for the participants to understand and use to help manage their health problem. As well, within this theme emerged the categories that served as a barrier for the participants in patient education experiences, vocabulary, or the medical discourse that is used, and the challenges of ESL for some of the participants.

Living Between Worlds

The participants felt that they lived between two worlds: The world of health and illness and the world of limited literacy and literacy. Because they had a chronic illness, they

perceived themselves as sick, not healthy, and therefore not like other people in society.

Also, because they went back to school to improve their literacy abilities, they believed that they were different from the majority of society, who they perceived as having no problems with literacy. The categories in this theme are engagement in society, overcoming adversity, and living in isolation. These categories reflect the experiences of the participants as they tried to situate themselves in society by engaging as much as they could yet were often faced with adversity in the process. The engagement into society was also balanced by the participants' recognition that they were living in isolation both due to their chronic illnesses and their limited literacy.

Engagement in Society

Participants recognized that living with their chronic illnesses and limited literacy made them different from other people. Participants felt that they didn't quite fit in, that they were living between worlds. Yet the participants also acknowledged that they felt that they should use their patient education experiences to help others who were facing similar health issues in their lives. This resulted in the participants trying to engage into society. For example, participants gave health advice to other members of their family, to friends, or to classmates. Addie had, in the past, given health advice to her mother and told her mother what to say when she went to her family doctor. She also advised her mother to take notes so they could talk about her appointment at a later time.

Nigist stated that she freely gave advice to other women in her exercise class about exercising, dealing with arthritis, and protecting themselves from injuries. Abeba gave advice to her sister about their mother's diet. She asked her sister to change their mother's diet so that she wasn't eating as much fat, and to get her mother to exercise more. It took some time for her sister to agree to this. Warda had, in the past, given health advice to her

family and her friends. She had also gone to doctor's appointments with friends who did not speak English and were nervous about going to the doctor.

Monique mentioned that she wanted to know more about her epilepsy and asthma to control them better and to help other people, "so you can tell them how it feels, information about the medication etc." As well, Monique understood that other people had difficulties with reading the patient education information and they needed someone to read the information to them, like her brother-in-law. Monique mentioned that she helped her brother-in-law by reading information to him and by explaining words when he had to go to a health care-related appointment.

Nyela commented that she felt much more part of society upon her return to school, "I know other people, I am not alone." She found this very helpful in dealing with her health problems as well.

Overcoming Adversity

For the participants, their feelings of living between worlds were also based upon experiences that they felt were unique, experiences that involved overcoming adversity. All of the participants mentioned an experience in their lives which could be seen as overcoming adversity. The participants had to overcome these challenges to feel that they fit into society, into the literacy world. Many times the beginning of overcoming adversity started when the participants were children and dealt with issues of schooling. For example, Louise had to leave school because her parents died when she was young. Carolyn left school because she became pregnant and a single mother at the age of 17. Both women knew that leaving school early had directly resulted in them having limited literacy.

Participants also spoke about the financial challenges or adversity they faced in living with limited literacy and a chronic illness. Carolyn felt that she had to leave the literacy

programs because she didn't have enough money to "get by," she could not "afford" to stay in school and "feed her son" through part-time employment. Nasreen also noted that she found it financially difficult. She began to receive the old age pension at the age of 65 and no longer received the ODSP income support. She found that there were differences in what was covered and what was not covered:

I got, turned 65, so they don't give my disability anymore. I receive retirement pension, so they, the, the, the difficulty I have is if I have asthma too, I need an emergency taxi, they don't give me an emergency, they give me before when I was on disability, so I am the same person I'm older I need emergency taxi. They say, no you are not on disability, you are on old age pension, so I'm older and I need it more.

A few of the participants actually received an ODSP income support due to their chronic illness or were awaiting approval to be on income support. Abeba received ODSP income support because of her arthritis. Before his car accident, Ramon had two part-time jobs; one entailed cleaning offices, the other was as a security guard. Chronic pain prevented him from returning to these positions. He thus began receiving ODSP income support in 1999. Sonia received financial support from the Ontario Works program and was awaiting approval for ODSP income support due to her tendonitis. She had previously worked in a dry cleaning business but had to leave due to her tendonitis. Addie had worked as a security guard in government buildings and was awaiting approval for ODSP income support due to her arthritis.

Living in Isolation

For the participants, their sense of living between worlds was reflected in their feelings of living in isolation. Lynn indicated that she felt very alone and isolated in dealing with her skin condition of Keloids. She stated that "I have never met anyone else with it

outside my family.” She felt that it would be nice to be able to talk to someone else so that she could learn from them. On the other hand, although some of the other participants had the same diagnosis of a chronic illness, they had unique experiences with the illness. This appeared to be somewhat dependent on how long they lived with their chronic illnesses. For example, the participants with asthma had all been diagnosed with the chronic illness for a number of years. In fact, both Sonia and Monique stated that they had had asthma all their lives. They had been told what medications they needed to take and had developed strategies to avoid triggers that might increase their symptoms. Of the participants with arthritis, Mekal had lived with it for over 30 years while Nigist had been relatively recently diagnosed in the last year. Therefore, their signs and symptoms of the disease varied.

There are varying degrees to which illness affected the participants’ lives. For example, Nyela had to check her blood sugar level everyday and, in her view, alter her diet significantly. Sonia, due to her asthma, had to take medications many times a day and had to make sure that she didn’t get exposed to any asthma triggers, such as perfume. She admitted that it was a challenge to avoid perfume because she would get exposed to it when she would ride the city bus to school.

All the participants said that everyone was different, so therefore their chronic illnesses were also different. Many participants mentioned that they knew that the illness varied among people. Warda commented, “it depends on the arthritis, you know some people have just beginner arthritis some people more worse you know, I don't think they tell everybody take the aspirin and be careful.” Nigist also stated that everybody's arthritis was different, “I didn't meet anyone else with arthritis they never say that ‘I have arthritis,’ I told them what is your problem, she tell me knee pain, maybe it could be arthritis but they don't say it.” Nyela also felt that everybody's diabetes was different; it was an individual condition

that could cause loneliness and feelings of isolation. Because participants recognized that everyone's chronic illness was unique, they also expressed the belief that it would be difficult for the doctor or others to tell people the same information. Monique thought that her doctor did not give the same information to all his patients with asthma or epilepsy because there were many different types of asthma and epilepsy.

Ramon mentioned that, in the past, he had talked to family and friends about their health problems and his health problems but he had not given health advice, because “everybody is different, everybody's condition is different, so you can only tell your own story.”

Summary of Living between Worlds

The categories in this theme reflect the participants' experiences of not really feeling that they fit into society perfectly. The participants felt that they were living between the world of health and illness and the world of limited literacy and literacy. Where they were in terms of these two worlds was constantly changing. They tried to give back to society and helped others with the knowledge that they had gained. They told of significant experiences in which they had faced adversity. They knew that their experiences in dealing with their chronic illnesses were unique and that they needed to help themselves, but this could be isolating at times.

Mismatched Expectations

Participants entered into patient education experiences with expectations of the health care professionals. The participants felt that there were essential components of their care that they anticipated to receive in their interactions with health care professionals. Unfortunately, these expectations were not always met. The theme of mismatched expectations includes the categories of respect, patient education, and time.

Respect

Respect was a strong aspect of mismatched expectations for the participants. Respect is defined as a “deferential esteem felt or shown towards a person” (Barber, 2001, p. 1228). Respect of the individual appeared to go both ways for the participants. They felt that they needed to respect their health care professional and that the health care professional needed to respect them as well. But, the latter did not always occur, these expectations were not matched with the participants experiences. Sonia related an experience that she had had in the emergency department, when her asthma became worse and she had difficulty breathing:

Sometimes just they don't treat you until they decide they are going to treat you, they are putting you to a lesson, they sit you there and wait, you wait, wait, wait and they say, “Are you feeling better now?” Because to them it is like you were walking here or you took the bus whatever and you were anxious and you were wheezing a lot but after you sit down and relax they go and check you, of course you are much better because you are not moving around and they take that and then I told one doctor one day that, ‘Ya but sitting around is not what I am going to do with my life.’

Sonia felt that she wasn't being respected as a person because the health care professionals in the emergency room did not believe her. Monique also commented about not being believed and therefore she felt that she was not being respected. She stated that these experiences usually occurred when people did not listen. Due to the fact that she had lived with asthma all her life, she had had many episodes of difficult breathing which resulted in her going to the emergency department. For many years doctors told her that she “was faking all the time,” that she didn't have a breathing problem. Her asthma wasn't correctly diagnosed until she was in labour with her son. She stated that finally people believed her and that was why she was diagnosed correctly.

Carolyn had had some experiences where she felt that she was not being treated the same as everyone else, that she was not being respected as a person. When she went to the hospital with her son, she found that “some of the nurses can be snobby.” Carolyn stated it's “kind of in the back of their head, this person's stupid like you're only coming in here for this, but do you know what I mean” and also “It's like they make you feel like you don't know what you're doing with your child.” She found that if the person had a “bad day or whatever they often take it out on the patient.” Carolyn would not ask questions if she felt a bad “vibe” from someone, because “I'm scared that you're going to either rip my face off or treat me like I'm some kind of idiot because you're having a bad day.”

Warda commented that there have been times when she received health advice that she felt she was being treated differently or being made fun of, that she was disrespected:

It depends on the person what does he mean, if he is just making fun of you, I don't want to listen to that, I am happy with myself but if you mean, the person he means it well for you, it depends on the connection, the reason.

Nigist mentioned the issue of respect as being a key aspect to a successful relationship between health care professionals and the patient; health care professionals need to “understand and be patient, and.. they don't judge anything you know sometimes, it's different culture it's different religion, it's the respect.”

Patient Education

All the participants expected to receive patient education information to help them deal with their chronic illnesses. Most of the participants acknowledged that they received information at the time of their diagnoses that made them think differently about their chronic illness. All of the participants mentioned, however, that they did not receive enough detailed health information to help them after their initial diagnosis. Three of the participants

changed their doctors because they thought that their doctor did not know how to help them deal with their chronic illness. Louise had changed her doctor because her previous doctor was not nice and had misdiagnosed her as having hepatitis. Ramon had switched doctors because he did not believe that his doctor explained things well enough. Sophia expected that she would be helped when she went to see someone, someone that would tell her about her condition. If she was not told about her condition, she did not go back because, “Why because I need help if I don't find it why do I do it a second time, if it is not working with me so I don't go.”

All of the participants wanted to know exactly what was going on with their chronic illnesses and how they could help themselves. Nigist wanted to know specific information related to her condition:

What food affect me, ya because I do diet which one is good for me and which one is not and I do diet, I control, most of the time I eat vegetables, and chicken and lots of meat and umm, ...which exercise work out first in my knee or which one is good for me and which one is not good for me because when I do exercise I'm like that so if I ask the person over there maybe I'll, they have to charge me, personal training money and it's too expensive but if someone has money they can afford it and can do personal training it's a good idea, you know, they know how they are controlling all things ... I did lots of sports and I hurt myself, ahh, and these happen you know.

Ramon felt that he had received very limited information about his chronic pain. He had a bit more information about his sleep apnea but he would have liked more specific details. When he first started having pain, the doctor didn't tell him that it would be chronic. Ramon mentioned that for the longest time he thought that he would get better and that the pain would go away. Eventually, he came to the realization that this was not going to happen

because no matter what he did to try to get rid of his pain, he still had it. He wished that the doctor had told him from the beginning that he would always have the pain. He thought that would have been better. Nasreen felt that she had enough information about what to eat and not to eat for her diabetes, but she did not have enough information about her arthritis:

I didn't get any information about this what to do, just the doctor he give me injection, some pain killer, so my arthritis got worse, on the, the shoulder and the bones, and I have now on my back bones arthritis, it's all the time with me and bothering me day and night, so that, I didn't get information about that too, besides the injections I had injections once a year or sometimes, but I have to have information to besides the medication injections.

Participants expected to be helped by health care professionals. Feelings of dissatisfaction appeared to emerge as a result of the participants having their health concerns dismissed or being told that there was nothing to be done about their illness. For example, Lynn expressed frustration in trying to get help about her Keloids. She had been living with her chronic skin condition for many years but was still being told by different doctors that she went to “that there is nothing they can do for her.” Lynn didn’t believe this and was still trying to find someone to help her. Lynn stated that she always felt frustrated after leaving her doctor’s office if the appointment was about her skin condition, “it’s frustrating because when you think there is hope and they will like dash the hopes.” Lynn’s reading ability had improved since she returned to school and she had thus been able to find information about her condition on her own.

Participants felt that they were not given enough health information on how to use medications. Nasreen commented that when she was prescribed medication for her asthma

she was not shown how to use her puffer:

I got this puffer and the doctor says okay that I have a difficulty with breathing and the doctor says "I give you puffer" and write the, the prescription. I went to the pharmacy to, the pharmacist give me a puffer and say "Okay, just the 2 puffs" and then the pharmacist doesn't explain it to me or the doctor explaining to me, how to open it and shake it, and then one puff and then I did it, how to do it, I didn't press it, puff and nothing happen, and then I didn't shake it, so that doesn't help those things.

This resulted in not only her information needs not being met, but also her physical needs.

Addie sometimes felt frustrated after leaving her doctor's office because she felt that he "sort of shoves me in the corner" and had left her with unanswered questions. She thought that he didn't answer her questions directly but went "around the bush."

Time

Significant mismatched expectations occurred for the participants in terms of time.

Participants felt that health care professionals should have had time to spend with them to explain things. Furthermore, participants expected they had the time and the opportunity to ask questions to the health care professionals but they did not believe that this time was provided to them. Lynn mentioned that she had found that

some doctors don't let you because they don't have, like they don't have enough time to listen, they don't have enough time, I remember one doctor he was talking and he was going out to, how are you going to ask this guy a question he is already out the door, how are you going to ask him a question, so it's the time.

Sonia felt that the doctors needed to spend more time with their patients, so that the patient would be able to actually tell the doctor why they were there for an appointment.

Instead of bang, bang, bang, take this, keep doing this, and they go. Doctors are

always in a hurry. Especially walk in clinics, bang, bang, go, you didn't finish to tell them what you had, they don't let you, you know, and how many times I have gone to a doctor for a bit of a throat infection and they didn't check your ears and a week later when I come back, there is an ear infection. So if they would sit down and talk to you about the problem and you would have a chance to figure out what you have.

Participants believed that the doctors didn't have enough time because they had too many patients. Ramon stated the he felt that if the doctors "were not rushed they could explain things to people better." Other participants expressed the same sentiment, that if the doctor spent more time with them, the doctor could better explain their condition. Warda felt that some doctors explain the situation they give you more detail about it and some they do not really it depends. Some of them they are, are, very patient, they care about patients, some of them are in a rush, you know getting you in and out, each doctor has different, you know, way to treat. And lately, I find that all doctors are in such a rush.

Participants indicated that they would filter the questions that they wanted to ask the doctor when they saw that the doctor was very busy. So, for example, if the participants had questions that were not about their primary chronic illness but about some other health concern, the participants would not mention it due to time. The participants made the decision whether or not their questions were important enough at the time to ask, but did not tell the doctor that is what they had done. Therefore, when the doctor asked them if they had any questions, the participants would say no. As Carolyn mentioned:

I know it could be a time issue with my doctor, he is extremely busy, so it's like when you get in there it is kind of like, you have to get your what you want to know out,

and it's like you're kind of weight them, you know, everything is important obviously but I mean you have to go for the main, the main points of what you need to know.

If the participants felt that the doctor was always rushing out of the room, then the participants were more likely to dislike the doctor and would not ask them questions.

Nasreen thought that the amount of time a doctor should spend with each patient depended on the situation. She had had an experience when a doctor she was seeing was very busy and didn't spend enough time with her. The doctor also kept her waiting:

If I ask him to check my, if I cough to check my lungs, he will check my lung and he check, asks me questions, ahh, my high blood pressure he check, it's a not too make me hurry before I had some doctor in the middle of the question and the examination that doctor said some nurse came and say telephone for you, I was sitting, sitting, now my doctor I am happy with, he doesn't make me wait.

Time was also an issue for the participants. Most had very busy lives, going to school, raising a family, and working outside the home. Carolyn said that even if she was given written patient education, "I don't have much time to read." Carolyn mentioned that she must balance the challenges of working full-time and being a single mother.

Warda expressed that she was dependent on the doctor's schedule and that of the larger health care system, not her own. She had been waiting for months to hear from her orthopaedic doctor: "He is supposed to call me for an appointment and he never called me and I have been waiting and I have been suffering with the pain in my elbow and nobody bother."

Participants also thought about other patients in terms of time. Mekal talked about thinking of others in the waiting room and not wanting to take too much time. Mekal would

therefore not ask questions to the doctor because he was more “attuned to how many people are sitting in the waiting room, I have been there for 20 minutes.” Sophia thought that if she was in serious pain then the doctor needed to spend enough time with her to find out what was wrong, but she didn’t want to take the doctor's time, “so I don't want to take another people's place so, they have right to, to get her time.” Unfortunately, this resulted in a vicious cycle.

Summary of Mismatched Expectations

Within the theme of mismatched expectations are many of the categories that are barriers for participants in their patient education experiences. There appeared to be a mismatch of what participants wanted and expected to encounter in patient education experiences and what their experiences actually were. They have had to deal with feelings of not being respected or believed and other experiences that lead to frustration. The participants expected to receive patient education so they could be responsible for their own health. They felt, however, that they had not received specific information that was adequate. In addition, the theme’s last category of time was a major factor in patient education experiences. The limited time of the health care professionals appeared to result in the participants feeling that they were not receiving all the information they needed.

Powerlessness

Power is defined in a number of different ways: energy, a faculty of mind or body, the ability to do or act, or authority or influence over others. Powerlessness is defined as a feeling of having no power or strength (Barber, 2001, p. 1136). The participants acknowledged their feelings of powerlessness in living with limited literacy and a chronic illness in a number of different ways. The categories within this theme are fear of exposure, obligation to follow advice, and establishing trust.

Fear of Exposure

The category of fear of exposure captures the feelings that participants expressed of embarrassment or their attempts to try to hide their limited literacy and their chronic illness which resulted in feelings of powerlessness. None of the participants had told their family doctors that they had any difficulties with literacy. Mekal mentioned that he had tried “to pretend that I am something that I'm not” while visiting his family doctor. He went on to say that “it is putting on an act to be something that you are not.” Mekal commented on how he did not want to tell his doctor and others in health care that he could not read because they would treat him differently. He thought that people would think “like he is slow and that someone should be with him.”

If Louise was asked if she could read, she stated that she would not answer the question, she would just ignore the person. She said that she did not think it was “anybody’s business” but her own. She knew that she could read, so that is all that was important to her. She therefore stated that “I don't get into it with them.” Louise did mention that she had covered up her level of education all her life. She left school when she was 12 years old and was “embarrassed that she had only finished grade 7.” Warda did not tell her doctor that she had difficulties reading and writing because it was a very private thing. People had never asked her if she could read in any health care situation.

Although there was the underlying worry that people would find out about their literacy problems, participants still found themselves in health care situations where they were faced with a literacy task that they needed help with. It appeared that in these situations, participants weighed the risk of having their limited literacy exposed with the risk of not getting care for their health problem. The participants therefore did not tell people they could not read. The participants would say, however, that they needed some help filling out forms.

For example, if asked if she needed help filling out health forms at her doctor's office, Lynn indicated that she did "because I know it is very important to give information you should give, you can give wrong information if something happened to you, its health, if something happened to you, what are you going to do." Lynn talked about how filling out pre-assessment forms before seeing a doctor was very difficult due to her limited literacy.

When you can't read and write it is very hard because it is confusing, but now it is getting better, because some form you don't know what to say and you don't want them to see, you know? You don't want them to know you can't read and write, you try to figure it out. Sometimes I feel bad because you don't know if they are asking you if like you are allergic to something and you may say no, but you may be allergic to. ...it is hard, it's scary too, when you come home or when you think about it. You said what about I'm allergic to something and I said no, is that their fault or my fault, or whose fault, you know. I think it is good area to look for it, it is scary.

Sonia, also spoke about the fear of exposure of having a chronic illness. She admitted that she did not want people to know that she had a chronic condition. Sonia revealed that when she first arrived in Canada, her sister told her to hide her puffers and not tell anyone that she had asthma. She was told she could be fired if her boss found out about her illness. She stated in the interview that she did not know her rights about working with an illness at that time of her life. One day while working in a dry cleaning business, her asthma became exacerbated by dry cleaning chemicals and her boss discovered her illness:

My boss, and he took me to the doctor and picked me up he wanted me to finish the work no matter what, I had a, I was very sick that day asthma and I was thinking I am very sick, but he didn't care, he just wanted the work done.

Obligation to Follow Advice

The participants had a feeling of powerlessness when they felt that they had an obligation to follow all the advice that they were given by health care professionals. The participants expressed that they did not have a choice. They felt that they must follow the doctor's advice because the doctor knew more than they did. This knowledge was a type of power over them that some appeared to resent.

Mekal mentioned that he felt that the doctor was like a superior, that he had to follow his instructions because he had authority over him: "He's the one in charge, I guess he is my superior, basically, okay, I don't know medicine, I don't know, umm, what I should be doing what I shouldn't be doing unless he tells me." Nyela mentioned that she felt that she had to follow the doctor's advice, "because he is a doctor and knows medicine" which "she doesn't."

Nigist follows her doctor's advice because,

he... knows, because it's his job, he knows because he has lots of experience maybe, people like me, they were there before me, and maybe they are cured now and that is why he gives me this advice to, so I listen to his advice and I did it.

The roots of these feelings of obligation lie in how the participants perceived the health care professionals. Louise followed her doctor's advice because

I know she is not Jesus, but she is in the medical field and she has more education than me, she should have to know something and again you use your own common sense too, and you have to think about your body also, because it is your body not her body, so you know what your body needs, she can tell you but you, yourself is the one that is in charge of your own body, so she is just helping you along.

The participants expressed that they needed to follow the health advice given to them, or had an obligation to follow the advice, so as not to offend their doctors. Lynn felt that it would be disrespectful to tell the doctor that you were not following his or her advice, because “it's kind of no respect because if you are here with me and then I say “take this” and you don't, there's no need to come again.” Addie had unpleasant experiences when she has told her doctor that she had not taken his advice. Her doctor, according to Addie, would get very upset at her and yell at her, but she stated that she still had to be honest with him. Lynn had to use a daily cream for her skin condition, but because she felt that the cream didn't help her condition, she didn't use it anymore. Addie had not told her family doctor that she was no longer using the cream. One of the reasons she had not told him was because he hadn't asked her if she was still using the cream. She did not want to bring up the subject because she was worried that if he found out she wasn't following his advice, he might not want to continue to have her as a patient.

Ramon commented that he found it difficult to follow his doctor's advice because although the doctor appeared to know about things, his doctor would give him general information about how to deal with his chronic pain but left Ramon to try “to figure out how that information relates to him.” He found that this was very difficult for him. He thought that the doctor knew this information, and that he should have given him the information. The participants also expressed difficulty in trying to follow health advice. Mekal, Nyela, and Carolyn all commented that, although they thought it was a good idea to follow the doctor's advice, many times it was impossible, because “they had to live their lives.” This led to frustration. They expressed that it was impossible to follow all the advice and still function in their activities at home, such as getting and bringing in the groceries for Mekal, who was not supposed to lift things. Mekal commented, “who else is going to do that.” Mekal stated

that he had tried to limit the amount of weight he lifted, he had tried to get his teenage son to help him as much as possible, but Mekal admitted that at the end of some days he had done too much activity and his arthritis pain was worse.

Carolyn would tell her doctor if she was not, for example, taking his advice about her medications. She always told the truth, because she believed that if the doctor didn't know that she was not taking the medication, the doctor would think it was the medication that was not working, and she would be given a new medication to try:

Because if something's going on with the medication, it could be because I'm taking it right or I'm not doing this right or doing that right, I think it's important that you admit to, to not listening or you know taking the advice because then the doctor, you're not punishing yourself, if you don't follow it right or if you lie to them and say, then they're going to be like okay well this medication's not working and you might end up with something worse. Which could lead to another problem with your health?

Carolyn also thought "that admitting to not doing something that creates a lie because you could be creating another health problem for yourself."

Establishing Trust

Feelings of powerlessness for participants often resulted from experiences in which either trust was broken between themselves and a health care professional or they never established a trusting relationship. Not surprisingly, if participants trusted and felt comfortable with their family doctor, then they asked questions. If they did not like the family doctor or another health care professional, they would not ask questions. Trust was important to establish to allow the health care professionals to fulfill their role as educator. Warda did not feel comfortable with some doctors that she had to interact with but she

believed that “you have no choice, you are stuck because it is hard to, you know, to find another doctor these days, you know, like you can feel comfortable with, that is my opinion, I don't know.”

Carolyn found that the health care professional's body language and sense of humour during her first encounter with them influenced whether or not she would trust the person. If she noticed that they appeared stressed or not receptive to her humour, that is, they did not laugh, she did not think that they cared and she did not trust them. She acknowledged that this may not be a fair way to judge people, but she mentioned that,

sometimes you have to so what I do is I see and I try to throw a little bit of humour and if they don't catch on to the bait it's over, okay you know that they're just, they don't care.

Trust can easily be eroded even if it had already been established with the health care professionals, as was the case with Louise, Carolyn, and Addie who had unpleasant or even frightening health experiences. For example, due to a mistake from a blood test, Louise was incorrectly told by her previous doctor that she had hepatitis.

When Carolyn was 17, she had to go into the hospital for about a month to have some tests run to figure out if she had a tumor in her stomach. She found that the doctors and other health care professionals did not give her a lot of information about what was going on. This lack of communication resulted in increased fear for her. Carolyn wished they had at least said that they didn't know what was going on, or that they were not sure, that would have been helpful to her.

One of Addie's doctors betrayed her trust by meeting with her brother behind her back. She changed doctors after this episode. The doctor also had wanted her brother to go to

Addie's appointments with her, but Addie told the doctor that "I am the patient, not my brother." Abeba believed that to help people improve their trust in their doctor, people should try to think of their doctor as family.

Like family, you can't be shy to ask the doctor because he's the doctor, you are not shy when you ask your mom things, it is the same thing, if you don't tell him and talk to him. How does he know when you have bad sick or not, you have to talk to him. Abeba believed that if health care professionals were "friendly, laughing, and getting close to their patients," building a friendship not just a professional, distant relationship, patient education would be more comfortable for the patients. This relationship could be further strengthened, according to the participants, if health care professionals asked patients what it was like for them living with a chronic illness. Carolyn commented that doctors and others in health care "should ask what a normal day for someone is, what do they have to do, what are their difficulties."

Participants have had to rely on others at times during their patient education experiences to help them with specific tasks, such as filling out health forms. The participants had ways to figure out if they could trust someone. They, in a way, had criteria for trusting someone. As explained by Louise:

you sit and feel them out, You sit down and you observe people and you see how they act and see how they talk and you see if they have a big mouth or would talk your business or you can tell them a secret, or you go tell them something and you see if they go repeat it. And if they don't repeat it and stuff and you can tell if someone is really, a really a true friend, a person that you can put confidence in or if you can't, you can tell just the way they act, how they don't act, you sit and you observe them. You can get a feeling, like, I could walk in here with you now for

instance I know we are not talking about you ... but you can tell if someone is on the up and up and you can tell if they are not on the up and up, you can just feel it.

Summary of Powerlessness

Within this theme, participants expressed their feelings of powerlessness in the face of having limited literacy and chronic illnesses. They felt powerless due to fear that people would find out about their limited literacy and their chronic illnesses. They felt obligated to follow health advice and challenged to try to establish trust in health care professionals.

Summary of Chapter Four

Chapter Four presented a profile of each of the 14 participants in this study. These profiles provided an opportunity to get to know the participants in more detail. The bulk of the chapter was devoted to the presentation of the themes and their categories that emerged from the data, revealing the patient education experiences of the participants.

The themes that emerged were different roles and relationships, living between worlds, language and health care interactions, mismatched expectations, and powerlessness. The different roles and relationships theme included the significant roles that different health care professionals play in the participants' lives, the roles that their family members including their children take on, as well as the role that the individual has in being responsible for their own health.

For the language and health care interactions, categories emerged which represented the different formats of patient education that the participants had experienced, verbal and written information, as well as the influence that vocabulary and English as a second language had on these experiences. The theme of living between worlds revealed the distinctiveness that participants felt in trying to live with limited literacy and a chronic illness within society. The theme of mismatched expectations highlighted the confusion and

frustration that exist for the participants when their patient education expectations were not met, either due to individual, contextual, or systematic reasons. As well, participants felt powerless in patient education experiences due to concerns that their limited literacy would be exposed. They also struggled with feeling obligated to follow advice at times when they did not trust their health care provider.

CHAPTER FIVE INTERPRETATION

This chapter further explores the findings by providing a structural description of the phenomenon using related literature including adult learning theories. The five themes found in the study are situated within the current literature pertaining to patient education, chronic illness, and literacy and health and related to adult learning theories. Situating the findings with the adult learning theories provides an opportunity to illuminate the components of the learning processes that occurred for the participants as a result of their patient education experiences.

Different Roles and Relationships

"The role or job of the health care professionals is to teach and explain your disease and give you advice on how to change your life." - Nyela

Within this theme were the roles and relationships of the health care professionals, the family members, and the individual participants. The roles of health care professionals, as perceived by the participants, included advisor, educator, and provider of health care treatment. Adequate communication skills were seen as crucial for health care providers to successfully carry out these roles. In a recent study conducted in California, 54 people with a variety of chronic illnesses were interviewed about their perceived barriers to active self-management (Jerant, von Friederichs-Fitzwater, & Moore, 2005). Themes emerged that related to intrinsic and extrinsic barriers. Intrinsic physical barriers included depression, difficulty exercising, fatigue, and pain. Extrinsic barriers included poor physician communication and low family support. Frustration with physician communication included disappointment of patients in their primary care physician who was unwilling to perform the role of referring agent to a specialist physician. The participants in this current study also expressed frustration with physician communication and that the physician was not doing

enough to help them. In contrast, the other extrinsic barrier of low family support was not a problem for the participants in this study, they had in fact overall strong family support for both their limited literacy and their chronic illness. Bakker and colleagues (2001) investigated patient-health care provider communication during chemotherapy treatment. Forty women receiving treatment for breast cancer were interviewed about their communication experiences with members of the health care team. The findings indicated that the women perceived that the different members of the health care team had different roles. For example, the role of the nurse was to help the physician and to act as a communication link between the physician and the patient. These findings were similar to the findings of the current study in which the participants also perceived different roles for doctors and nurses with whom they interacted.

Similar to the current study, the study of the Centre of Literacy of Quebec (2001) found that patients perceived that their family members played particular roles in helping them manage their healthcare. For participants in this study, family members were perceived as holding the role of interpreter, reader, and mediator when there were barriers to communication with members of the healthcare team. These different roles were also noted in the Baker and colleagues study (1996) in which participants spoke of bringing a family member to appointments to help them navigate the health care system. Baker and colleagues noted that some participants would not go to a doctor's appointment unless someone who could read went with them. Participants also described the role of mediator or translator for family members, especially children; this has also been noted in the literature. The term that is also used for a family member is language broker, and the act of translation might better be described as para-phrasing (Faulstich-Orellana, Reynolds, Dorner & Meza, 2003).

Faulstich-Orellana and colleagues (2003) noted that children will phrase things for their parents, to help them in their social roles, such as dealing with health information.

That individuals with limited literacy require a third party to help them cope with the health care system raises an important concern. The presence of family members may limit an individual's ability to present his or her concerns to a health provider. Good and Good (1994) in family narrative studies, found that different family members had different perspectives on the patient's illness, with alternative plots and possible endings. When the family member is a son or daughter, which was the case for their participants, they tended to assume a parental role, leaving the actual parent in the role of a child. Health care professionals may encourage this by talking to family members, with whom they better identify, rather than speaking to the patient directly. This role reversal could lead to confusion and frustration. Although the participants in the current study did not express this frustration, at times their children did take on the more knowledgeable role, similar to a traditional parental role. Bringing someone else into a health care interaction and possibly into the discussion of making a major decision could result in the person with limited literacy not having a sense of mastery or self-efficacy in the situation. According to Bandura (1982), self-efficacy is our own estimate of how competent we feel we are likely to be in a particular environment.

There was another important health-related connection between the participants and their families. The health of the participants could have an effect on the health of their family members. For example, in this current study, one of the participants, Sonia, had asthma and her son also had asthma. Sonia had some difficulties in managing her own asthma due to her limited literacy; so she could also have difficulties managing her son's asthma. The link between the health of the participants with limited literacy and their families was detected in

the work of Gillis and Quigley (2004) in which they noted a “strong link between the literacy level of adults and their physical, mental, social and economic health and to a strong impact, direct and indirect on their families and communities” (p. 24).

As mentioned previously, patient education for someone with a chronic illness is geared towards self-management; that is, the objective of the education is to assist individuals in this role of maximizing and maintaining their health through learning and carrying out actions to control the effects of the illness.

Language and Health Care Interactions

“It’s health so the person has to know what she and he is signing or listening to, so I think it is very important.” Lynn

It is certainly not surprising that language and health care interactions was a theme that emerged from the data of this study. Within health care interactions participants had to deal with both verbal and written language. Issues of language have been raised in the majority of qualitative research studies in the area of literacy and health (Baker et al., 1996; Brez & Taylor, 1997; Centre for Literacy of Quebec, 2001; Gillis & Quigley, 2004). Baker and colleagues (1996) investigated the health care experiences of people with low health literacy in the USA and noted that language issues contributed to barriers to the navigation of the health care system, including difficulties deciphering complex forms and provider-patient interactions in which complicated medical language was used. In terms of provider-patient interactions, participants noted that health care providers did not listen to them or explain their medical problems and treatments in a way they could understand. Participants in the Centre for Literacy of Quebec study (2001) acknowledged that they needed information to be repeated later on in their treatment. The results from both these previous studies were in line

with the findings from the current study, in which participants expressed confusion and misunderstanding after verbal interactions.

This confusion might be because the language used in health care interactions often excludes rather than engages the patient. This was the case for the participants in the current study. Such language can be seen as technical discourse (Lemke, 1995). Technical discourse is communication that acts as “tools of power to further projects and agendas of some already dominant group” (Lemke, 1995, p. 12). Bakhtin (1981) believed that “authoritative discourse demands our unconditional allegiance” (p. 343). Therefore, the use of such discourse reinforces the imbalance of power.

Unfortunately, written patient education information is greatly influenced by this discourse. This is an issue with all patients but can greatly affect patients with limited literacy skills. This discourse may be the major reason that Rudd, Moeykens, and Colton (2000) found, when reviewing patient education materials, that most “standard patient educational and care practices are insufficient to overcome the barriers presented by inadequate literacy skills” (p. 183) in the United States.

This could certainly lead to people, who feel that they have adequate literacy ability for most aspects of their lives, having feelings of inadequacy in health care interactions and even labeling themselves as stupid. Having a label can have an influence on how a person perceives themselves within society. Clark (2003) describes the labeling and unlabeled of a female college student who had been labeled with a learner disability. The student had accepted this label, even though up to that point she had always done well in school, despite the fact that she had done all of her studies in English when her first language was Spanish. The student had taken on the label of learning disabled in college, Clark argues, due to the fact that the label had come from an authoritative discourse, a psychologist report. The

student recognized that she did not have a learning disability through her social relationships with other students in class.

This is similar to the experiences for the participants in this study. The participants may not have been labeled by others as being stupid, but they had been living in a society in which limited literacy is equaled with stupidity and laziness. It was not until their interactions with others in their literacy classes, that they realized they were not alone with their limited literacy experiences and that others shared their challenges in dealing with the authoritative discourse of the larger society.

Although patient education can be delivered in many different formats, the two main forms that participants in the current study encountered were written material and verbal interaction. These forms were often used in conjunction with each other. This is not surprising since health care professionals are often encouraged to give written information to supplement their verbal instructions (Lorig, 2001). Written patient education material came to the participants in many different shapes. These included pamphlets from the doctor or pharmacist that list specific drug information, and materials towards health promotion for the general population. Participants did not find the written information that they received to be helpful and therefore they did not usually keep it as reference material. One of the main reasons for this was due to the vocabulary used in the material that the participants did not understand.

The issue of vocabulary has been noted in a recent multi-centre qualitative research study whose purpose was to uncover the body and health knowledge of individuals who were identified as being at risk for coronary heart disease (Angus et al., 2005). Eight focus groups were conducted in urban, rural, and Northern Ontario, and these included First Nations people, Francophones, Anglophones, and immigrants. The authors noted that some

participants struggled with the specialized language of the health sciences. Yet in analyzing the transcripts of the interviews of the focus groups, the authors noted that participants tried to use medical terminology. The authors concluded that the participants had learned a new language through their exposure to health care. It appears that to engage with health care providers, participants had to learn at least some of the vocabulary of the language of the health care providers. Within the current study, all participants expressed difficulties in understanding the health care provider when she or he used medical terminology or vocabulary. This might be particularly challenging for individuals for whom English is not their first language. Within the Centre for Literacy of Quebec (2001) study, participants also were not satisfied with the oral communication with health care providers; they felt that there were language barriers when the health care provider could not communicate in the patient's language (p. 20).

Certainly, the issue of interacting with a health care provider for a patient in a language in which they are not completely fluent is a reality for many people in Canada. English was not the first language for 9 of the 14 participants in this study. Three of these nine actually had family doctors who spoke their first language. These three participants noted that although they spoke the same language as their family doctor, they still did not understand all the words that the doctor used. Moreover, these nine participants were immigrants. The IALSS results revealed that a larger proportion of immigrants have low literacy compared to citizens born in Canada (Statistics Canada & Organisation for Economic Co-operation and Development, 2005). This has implications for the health care system, especially in terms of chronic illness management programs and initiatives which will be discussed in the following chapter.

Living Between Worlds

“Their problem it is not public it is personal, it’s personal. I don’t understand it is not your problem, it is not your fault. I am the wrong one here.” – Sophia

The participants expressed that they live between two worlds. Because they have a chronic illness, they perceive themselves as different from others in society who are well. Also, because they have gone back to school to improve their literacy abilities, they believe that they are different from the majority of society whom they perceive as having no difficulties with literacy. The participants try to situate themselves in society by engaging as much as they can, but are often faced with adversity while trying to do this. Despite this engagement in society, the participants felt they were living in isolation due both to their chronic illnesses and their limited literacy.

As individuals living with chronic illness, the participants experienced periods of relative wellness in which their health was stable; these periods were punctuated by health crises in which they needed to seek medical care. They therefore sometimes lived in the world of the well, and sometimes lived in the world of the sick. This is in keeping with the recent conceptualization of chronic illness derived from a metasynthesis of 292 qualitative research studies. The “Shifting Perspectives Model” proposes that individuals with chronic illness alternatively experience the illness as the foreground or the background of their lives, and that this could alternate over the course of the person’s life (Paterson, 2001). This is seen as an on-going, continually shifting process in which people experience a complex dialectic between themselves and their “world” (p. 23). This changing aspect of chronic illness is similar to what Morse (2000b) referred to as the “constant state of flux” (p. 539). The shifting of perspectives could lead to feelings of social isolation. This was the case for participants who were unable to go to their literacy classrooms due to worsening symptoms

of their condition. For example, Warda found the interaction with other students at school enjoyable, but she had to miss class when an exacerbation of her arthritis made it too painful for her to sit for extended periods of time. This variability in living with a chronic illness was also noted in the Ashe and colleagues (2005) study that looked at the experiences of individuals with arthritis who attended health education groups. Three themes emerged from the study: 1) “validation through connection” (p. 284), 2) “the restructuring illness identity that emerged from the participants” (p. 285), and 3) “perceptions of self and disease symptoms” (p. 285). All three of these themes are similar to the feelings of living between worlds, living in isolation, and trying to connect with others as noted among the participants of the current study. Social isolation was also mentioned in the Gillis and Quigley (2004) study in rural Nova Scotia, in which they noted feelings of isolation related to the physical isolation of a rural community.

In the findings of the Brez and Taylor (1997), study participants noted that they thought that if they were discovered to have limited literacy, then they would not be accepted socially. However, it should be mentioned that the participants in the Brez and Taylor study noted that the hospital was a special place where they felt safe to tell people that they had limited literacy. This feeling may be due to the fact that the participants felt they were part of the hospital, because they had a role there – they were the sick patients. This feeling of belonging engendered a sense of safety.

Participants’ feelings of social isolation and living between worlds are not surprising considering that individuals with low literacy are generally viewed as marginalized from the larger North American society. Freire (1970) noted that often times within society, people who are oppressed are treated as “marginal persons who deviate from the general configuration of a ‘good, organized and just’ society. The oppressed are regarded as the

pathology of the healthy society” (p. 74) and they are expected to integrate into society.

Freire proposed that these marginalized people are part of society already, and live inside the structure that made them. They only are marginalized in relationship to the “norms” of society that they lived in and whose routine workings produce them.

Mismatched Expectations

“I educated myself on how to breath, some people don’t know about this, you know, it wasn’t introduced to them or they just don’t care.” – Sonia

In the present study, participants reported entering into patient education experiences in which their expectations of the health care provider often were not met. The theme of mismatched expectations emerged from the following categories: respect, patient education, and time.

The participants went to see their doctors and other health care professionals because they recognized that these individuals had health information or knowledge that they needed to manage their health concerns. The participants’ point of view was that health care professionals needed to share this information with them. The participants’ mismatched expectations seemed to occur because the participants perceived that the health professionals did not appear to share this same point of view. Interestingly, none of the participants in this study had heard of the term “patient education,” even though that is the common term for health information or advice from a health care professional’s point of view.

These differing points of view may be due to patients’ and health care providers’ exposure to different concepts of health care during their development. Wells (1999), in reviewing the work of Vygotsky and Halliday, noted that both theorists believe that “an individual’s development and social and cultural change, occurs through the individual’s linguistically mediated internalization and subsequent externalization of the goals and

processes of action and interaction of these activities” (p. 48). Physicians and other health care professionals, because of their orientation, schooling, and socialization, were exposed to and use a medical conception of care and treatment (Hydén & Mishler, 1999). They may have so internalized this medical conception of health that they may not discuss actions that the patients need to do on their own. They assume that the patients know what these actions are and how to perform them because this is “just common sense;” no discussion of these actions then is seen as necessary. For example, a physician may not tell a person with arthritis in their knees that they could use ice on their knees to help with the arthritis-related swelling and pain, because the physician assumes everyone knows this. Similarly Angus and colleagues (2005) concluded that “lay understandings of the body and health differ from those of health professionals and educators, and that lay understandings differ according to SES [socioeconomic status] and gender” (p. 2117). In that study, participants who “had higher education and greater experience with the abstract lexicon of the sciences” were better able to understand and describe issues associated with heart disease compared to others in the study (p. 2122). The participants felt that the health care professionals knew more than they did about the medical conditions they faced and they expected that the health care professionals would share this knowledge or information with them.

This recognition that health care professionals are experts with specialized knowledge that patients wanted to and needed to know has been noted in a study of the needs of women during cancer care by Baker, Fitch, Gray, Reed and Bennett (2001). Participants acknowledged that the providers had the “power and control at the beginning of treatment phase and in all interactions” (p. 64). Health care professionals “offered full explanation and encouraged discussion, through interactions,” the women viewed this as a positive use of the health care professionals’ power and control (p. 65). Health care professionals having power

and control is in keeping with the historical perception of the relationship between women and physicians in Canada. According to Mitchinson (2001), traditionally in health care interactions “the physician was the rescuer and the woman the rescued” (p. 95). The physicians’ role of rescuer has been altered in more recent years as patients have increased their voice in health care interactions. Patients are expecting to be more equal partners and, as Mitchinson discusses, the present feminists’ vision of the health care system is of one that should be more caring and which allows and encourages patient agency. For example, health care professionals need to provide patients with alternatives to choose from for advice.

This is similar to the findings of the current study in which participants expressed frustration at not receiving patient education or not receiving specific enough information. As well, in the Angus and colleagues (2005) study, health care professionals were regarded as “brokers of important knowledge about the human body in general and the participants’ own bodies in particular” (p. 2124). This is also similar to the Reid and colleagues (1995) study that found a mismatch between what health care professionals thought was important for the patient to know and what the patient wanted to know when reading an information pamphlet about diabetes. Participants in the current study were frustrated when their need for specific knowledge related to their particular health condition was not given.

The recognition that health care providers bring their own expectations to health care interactions was noted in an important policy paper from the Institute of Medicine (2004). The authors concluded that “health literacy goes beyond the individual. It also depends upon the skills, preferences, and expectations of those health information providers: our doctors, nurses, administrators, home health workers, the media, and many others” (p. 2).

In addition to having particular expert knowledge with regard to illness, health care providers also demonstrate a tendency to see health issues as being exclusively about the

body. This may limit the health care providers' ability to perceive health information needs related to coping with health problems in a broader sense, or to recognize the information needs of family members. A significant finding of the Centre of Literacy of Quebec (2001), was that "patients and professionals have different perceptions of the health education needs of this group and that their family members want different information than patients" (p. 18). For example, family members expressed the need to know about "patient's feelings and ability to cope, how the illness would affect the family life and where to find health resources" (Centre for Literacy of Quebec, 2001, p. 18).

In addition to expecting health information, the participants in the current study had also an expectation of respect from health care professionals. This also was noted in the Centre of Literacy of Quebec's (2001) study, in which participants in that study expressed the "need to be listened to and respected" (p. 18). Respect is seen as key in establishing trust and therefore allowing for effective communication between health care providers and themselves. If the respect was not there, then the relationship was not there and no effective communication occurred.

Finally, within the theme of mismatched expectations was the category of time. Participants felt that there was inadequate time during health care encounters for their concerns to be addressed, but were also aware that they did not want to take too much of the time because they knew other patients needed to be seen. Health professionals recognized the need for more time to teach patients that they had labeled "hard-to-reach;" however, they felt that this time could not be found within the current system (Centre for Literacy of Quebec, 2001, p. 25). This unfortunately appears to be a vicious cycle in which both patients and providers are aware they need more time, but at present, there is no more time in the system.

Powerlessness

“In my opinion, if you can’t read and write you are treated differently, how do I put it, you’re a subclass, you are inferior.” Mokal

The findings that emerged from this study indicate that the participants felt relatively powerless. Their feelings of powerlessness including the feeling of fear of exposure were rooted in the experience of living with limited literacy. This finding is consistent with previous studies. Individuals with limited literacy have reported living with shame (Breen, 1992) and fear of being exposed in a social setting including the health care context (Parikh et al., 1996). As well, people with limited literacy have previously mentioned that they feel fearful, anxious, angry, stupid, embarrassed, and ashamed and are suspicious of others within health care settings (American Medical Association, 1999). Brez and Taylor (1997) also identified the stigma of illiteracy. Furthermore, none of the participants had told their family doctor about their literacy problems. Baker and colleagues (1996) reported that few participants had told their health care provider about their reading difficulties because they felt embarrassed to tell the doctor they could not understand.

Participants in the Centre for Literacy of Quebec (2001) felt particularly powerless to ask questions to health care providers. They expressed worry and fear “that their question might be about something that has already been explained” (p. 30). They felt that such a demonstration of lack of understanding would affect their relationship with the provider. Participants in Gillis and Quigley’s (2004) study reported a feeling of powerlessness as they “spoke of a lack of control over situations in their daily lives, which they frequently attributed to their lack of literacy skills” (p. 30). Participants felt powerless because they did not receive the specific enough health information to help themselves. They had a sense of

being kept in the dark due to the fact that they did not have information or they felt that the health care professional was withholding information.

The theme of powerlessness is certainly not unique to people living with limited literacy. Relationships between health care providers and recipients have often been noted to be based on power (Foucault, 1973; Morse, 2002; Skelton, 1997). Many people are still reluctant to directly confront authority figures such as health care professionals. Often this is a case of not feeling entitled because they are not in the same class as the authority figure. The knowledge and expertise that health care professionals possess, in addition to the social class or status that they still hold in society, all lead to an imbalance of power. The relationship of health care professional and patient is similar to both a teacher-student relationship and a parent-child relationship. One person is seen as more knowledgeable and experienced than the other; the less experienced individual is expected to defer to the other's opinions and suggestions. This sense of entitlement is similar to whether or not a person feels they have a voice, that their voice is heard. Even though the participants in this study recognized that their literacy abilities were improving, they were aware that they did not have a complete knowledge of medicine and therefore they had to situate themselves in main stream medicine, so as to get help for their condition.

This results in asymmetry of power is exhibited in many ways. For example, when a patient wants to see a physician, the patient must make an appointment; the timing of this appointment depends more on the physician's availability than the patient's schedule. Even the physical environment or setting of an interaction is a power issue. Rarely do health care interactions occur in patients' homes; rather, they tend to take place in the health care professionals' office, clinic or hospital. The health care provider is therefore in a familiar and

comfortable setting, while the patient must deal with unfamiliar surroundings (Hydén & Mishler, 1999).

The imbalance of power also includes a physical imbalance. Generally speaking, the health care provider is at least well enough to work, while the patient is experiencing illness and resultant physiological or psychological stress. Furthermore, the patient may be experiencing pain, fatigue, confusion, anxiety, and/or decreased physical strength as a result of their condition. As well, the medications that the patient has been prescribed may increase fatigue and decrease the ability to concentrate. These will all have an effect on the patient's ability to learn (Toman, Harrison, & Logan, 2001) and engage in reflective discourse.

This section of the chapter integrated the findings that emerged from the data with the current work in literacy and health, patient education, and chronic illness literature. The themes of this study are in line with many of the findings from the few previous qualitative research studies conducted in the area of literacy and health.

The uniqueness of this study is its focus on the meaning of the actual learning process in the patient education experiences of individuals with low literacy who are living with chronic illnesses. Through this study, the components of the learning process involved for the participants were uncovered. For example, components such as when learning occurred or how learning did or did not take place, and the barriers involved in learning were revealed. The second part of this chapter situates the findings regarding these components within the context of adult learning theories. This is in keeping with Van Manen's (1997) suggestion that a researcher needs to maintain a pedagogical orientation to the phenomenon as a key research activity, as well as a structural description of the phenomenon.

Adult Learning Theories

All participants in this study experienced patient education. It could be argued that patient education experiences are constructivist activities; the learner participates by, or in, constructing new knowledge. Similar to other adult learning experiences, a person comes to a patient education experience with previous knowledge and experiences about what it is like to live day to day with a condition. Through patient education experiences, the person is introduced to new information. The person will take this new information and place it into the context of their previous experiences, with the result that new knowledge to help them deal with their health condition is constructed.

Within the current study, patient education experiences were not isolated events. Rather, they were multi-phased, and involved various health care providers, family members, and friends. Over years, the participants built up knowledge, developed skills, and changed behaviour. When they were first diagnosed, the participants were given information about their condition. As the symptoms of their chronic illness altered, the participants often were provided with new information which they had to incorporate into their previous knowledge of the condition. As well, the participants were often prescribed different medications or treatments to help combat their changing symptoms. The participants then had to develop new skills, such as using a bronchodilator to manage their asthma or measure their blood sugar level with a blood sugar monitor to manage their diabetes.

The following section of this chapter will use selective quotes from the participants to provide specific examples of their learning which will help to structure the findings within the three selected adult learning theories: transformational learning, situated cognition, and critical theory.

Transformational Learning

As stated previously, transformational learning theory provides a basis for understanding how adults interpret and make sense of their experiences and act in their worlds. The theory attempts to explain how adults use critical reflection in learning. Transformational learning theory's key concepts, meaning schemes, meaning perspectives, and critical reflection, have been previously introduced.

Mezirow (1995) believes that there are four types of learning. One is learning within meaning schemes, which involves learning to “add, further differentiate or integrate ideas within a pre-existing” idea (p. 49). The second involves learning “a set of beliefs, feelings, and judgments” to form new meaning schemes, when the person did not have these schemes to begin with. The third type of learning is a type of transformative learning in which, through critical reflection, meaning schemes are changed. The final type of learning is a more substantive type of learning transformation; it involves the transformation of meaning perspectives. For this final type of learning, Mezirow (2000) believes that the learner must engage in content, process, and premise critical reflection.

Perspective Transformation

This section will introduce and illustrate through the use of study data, the 10 phases that Mezirow (1991) has postulated in his earlier work to occur during the meaning making process of perspective transformation. These steps are: (a) a disorienting dilemma, (b) self-examination with feelings of guilt or shame, (c) a critical assessment of epistemic, sociocultural, or psychic assumptions, (d) recognition that one's discontent and the process of transformation are shared and that others have negotiated similar change, (e) exploration of options for new roles, relationships, and actions, (f) planning a course of action, (g) acquisition of knowledge and skills for implementing one's plans, (h) provisional trying out

of new roles, renegotiating relationships, and negotiating new relationships, (i) building of competence and self-confidence in new roles and relationships, and (j) a reintegration into one's life on the basis of conditions dictated by one's new perspective (p. 168-169). These phases are not necessarily linear; the learner might move back and forth between some phases along the way. Mezirow has also commented more recently that these phases should not be seen as of equal length, some appear to be more significant than other phases in the process (2000). As well, the context of the learning situations will have an impact on the process. This process occurs because the learner wants to learn (Mezirow, 2000).

The first phase or component for the learner is a disorienting dilemma. For the participants, this dilemma was the diagnosis of their chronic illnesses. When first diagnosed with a chronic illness, all of the participants brought with them feelings, understandings, and beliefs related to at least some of their chronic illnesses. These made up their meaning schemes and meaning perspectives. For example, Mekal, Abeba, Louise, Warda, and Nigist all had arthritis and they had previously heard the term arthritis. Their previous meaning schemes, however, held some misleading preconceptions and they thought that arthritis only affected old people and therefore they could not have it because they were too young.

Nasreen had some previous knowledge of diabetes; she thought that you should not "eat too much sugar, because you will get sugar on your blood." Sophia, who had asthma, thought this disease was "something that you were born with, and you would know that you had asthma when you were a child, not as an older person."

Within the second phase, there is self-examination of what this disorientating dilemma might mean for the learner. Often this is accompanied with feelings of shame or guilt. Participants did not express any feelings of shame, but some had some feelings of guilt that they might have been able to prevent their chronic illness. Some blamed themselves.

Nasreen and Nigist both thought they might have been able to prevent getting arthritis.

Nasreen thought she might have gotten arthritis due to the fact that she had not consumed enough milk when growing up. Nigist was told that she might have gotten arthritis because she worked too hard and might have injured herself lifting and carrying heavy objects during her household chores.

It appeared that the beginning of the critical assessment and reflection step began for the participants when they were first diagnosed with their chronic illness. Theoretically, this step involves an assessment of epistemic, sociocultural, or psychic assumptions, and this certainly was the case for the participants. Some participants did not believe that they had the condition when first diagnosed. This included both participants who had heard about the condition previously, as well as those who had never heard of the condition. It appeared that Mekal's critical reflection occurred not as a single event, but over time as things got worse for him from a physical abilities point of view. Over the years, he became convinced that he had arthritis because of his physical limitations.

Within the fourth phase, there is a recognition by learners that such feelings of unease with changing how they think have occurred in others who have been in similar situations, and that these other people were able to negotiate similar change. For the participants, their engagement in their literacy classroom allowed them to explore health concerns with others in a safe environment.

As learners start to think about things a bit differently, they explore different options for new roles, relationships, and actions. This occurred for the participants. It took some time before Mekal, Ramon, and Sophia believed their diagnosis. This did not occur until their symptoms persisted or became worse; then they realized that they really had the condition and they needed to do something about it.

For Mekal, this lack of confidence in the diagnosis was related to his meaning schema for arthritis. While Ramon did not question his diagnoses, it took time before he recognized the long-term nature of his illnesses. At first, he thought that his sleep apnea would disappear after using the continuous positive airway pressure (CPAP) breathing machine that “it would cure him” and he would not have to use it for the rest of his life. Ramon thought that his chronic pain, related to previous injuries, would resolve at a certain point in time. After the pain persisted despite physiotherapy and other treatments, Ramon came to the realization that he may have to live with the pain all his life. Ramon’s previous meaning scheme to explain his pain was that his pain would eventually go away with treatment. These meaning schemes changed due to the fact that his pain did not resolve. This change in meaning schemes included the introduction of the concept of chronicity, meaning that his condition was chronic or long term, something that he would have to live with for the rest of his life.

Patient education could be seen as an attempt to deconstruct old meaning schemes and perspectives and construct new meaning schemes and perspectives. There was evidence that this, in fact, did happen. All the participants expressed the sentiment that after receiving health information about their condition, they started to think about it differently. They acknowledged a change in their way of thinking about the condition. But this took time; it seemed to occur only after several sessions, often with several different health care providers. This change in thinking also occurred as a result of their improved literacy abilities.

Abeba had previously thought that arthritis was “bone sickness” when the “bones fill with fluid because you do not have enough calcium in your diet.” After her family doctor told her that she had arthritis, she thought that it was “tired bones” and she could do nothing about it. She stated that it was not until she saw a specialist, who told her that her arthritis

was relatively mild and that she could be helped with medication, that she really understood her condition. Similarly, Louise reported that after the doctor told her a bit more about arthritis, she realized that she did not know that arthritis can “deteriorate” the bones.

The sixth phase is a continuation of these new roles. In this step, learners plan new courses of action to address their changes in thinking about their situation. For the participants, this was the beginning of planning some behavioural change to manage their chronic illnesses. Nasreen found that she changed the way she thought about arthritis following patient education. She previously thought arthritis meant that the bones were “very soft.” She was afraid to exercise because she believed it might break her bones. In patient education, she learned that exercise was beneficial to people with arthritis. The doctor had told her “No, the more you move the better.” Nasreen stated “then I started [to exercise] and I feel better than before times when I was careful [and didn’t do exercises].”

To implement these new changes in action, participants’ recognized that they needed to acquire new knowledge and skills. Addie’s improvement in her literacy abilities allowed her to find information about her arthritis. Because she knew how to find information and could read about arthritis, she believed that she thought about arthritis differently. Addie also “knows what to take to combat it.” This had also helped her control her arthritis. This learning could be seen as increased confidence in her ability to manage her chronic illness. Because of learning how to read and write better, Louise felt that she also understood more about her health and asked more questions. Louise was able to go to the health food store and look for the vitamins. She was also able to ask questions to the pharmacist about her high blood pressure. In addition, Louise noted that she

can read books. And I can read up about it [arthritis and high blood pressure] and find out what's all about like. I have a medical book at home which I have to unpack and it will tell you about arthritis and high blood pressure.

Within the eighth phase, learners begin to try out these new roles as their meaning perspectives start to change. This results in them renegotiating relationships, developing, and negotiating new relationships to take on these new roles. According to Mezirow (1995), this step can be “very threatening, emotionally charged and extremely difficult” for the learner (p. 48). This step occurred for the participants as they began altering their role in health care interactions. For example, Nyela was able to attend health appointments alone, rather than with her husband, as she did in the past. Since returning to school, she understood more and so she could go by herself. In the past, she noted that she did not feel comfortable in going to the appointments alone, because she worried that she would not understand what the doctor said. Changing this role of being more dependent on her husband to less dependent was not easy for Nyela, it took some time.

As the learner enters into the last phase of perspective transformation, they begin building competence and self-confidence in new roles and relationships. This certainly was the case for the participants. For example, Nasreen indicated that she actually changed her eating behaviour after receiving health information on diabetes at a community centre.

They had one program. To how much you eat and what to eat and what not to eat. So first I thought, the doctor told me ‘so you have diabetes.’ I thought okay I don't eat the sugar or sweets. When I saw the program. Everything I eat is a sugar, rice. The amount of rice I eat a full plate. Now I'm not eating full plate. I eat a quarter of a plate, one half rice, then vegetables, (cough). I usually drink, ... I was drinking juice

a lot of coke, and I don't use drink juice, I drink coke a lot, [now] I drink water with my supper.

Nasreen's behaviour change appeared to have been the result of a change in her meaning schemes about how her diet might be affecting her diabetes.

The final phase in perspective transformation is one of reintegration of these new perspectives into one's life on the basis of conditions dictated by one's new perspective. In this study, the practical changes and integration into their lives was accorded through their interactions with the educational system. Participants felt that improvement in their literacy skills had actually improved their health status by improving their ability to understand and use patient education information. These improvements fell into four areas: (a) participants were better able to understand and participate in verbal interactions with health care professionals, and participants felt more comfortable and confident asking questions in health care situations when they did not understand; (b) participants were better able to independently read and fill out health care forms by themselves; (c) participants were better able to independently look up information from written materials; and (d) participants felt more confident attending health appointments alone.

Therefore at an individual level, it appears that the participants' patient education experiences resulted in a shifting of meaning perspectives related to their chronic illnesses. Their diagnosis appeared to be the disorienting dilemma which began the process. The majority of the participants had had previous knowledge or understanding of their chronic illnesses but these meaning schemes and perspectives required alteration before they adopted the behaviors recommended for the management of these diseases. Participants' meaning schemes were deconstructed and reconstructed resulting in the meaning schemes being transformed as a result of their patient education experiences and improved literacy abilities.

Participants also began the process of perspective transformation, which resulted in behavioural changes for the participants, the ultimate goal of patient education geared towards teaching self-management strategies for living with a chronic illness.

Although transformational learning theory is helpful to explain some of the learning aspects of the patient education experiences from the participants' perspectives, not all the factors that contributed to their learning can be accounted for through this theory. Situated cognition can be useful to understand how the context of patient education experiences shaped the learning experiences for the participants.

Situated Cognition

As previously noted, according to situated cognition theory, learning is a complex interactive and collaborative social phenomenon. Knowledge is situated in the context in which it is constructed. Within situated cognition theory, the learner, the learning process, and situation in which the learning is presented are intertwined and can not be separated. Situated cognition theory's key concepts are: anchored instruction, cognitive apprenticeships, and situated learning (Merriam & Caffarella, 1999).

Anchored Instruction

Anchored instruction refers to instruction in which the material to be learned is presented in the context of an authentic event that serves to anchor or situate the material, allowing it to be examined from multiple perspectives (Barab & Duffy, 2000). Anchored instruction occurred both within patient education provided in the healthcare or community sector, and within the discussions in the literacy classes. For example, Sonia felt that she learned more during a visit to the doctor when he used models and diagrams to explain how the body worked, instead of just talking to her. The learning experiences in the literacy classroom appeared to be closer to real world experience than more abstract instructions often

experienced by the participants in healthcare settings. For example, Abeba felt that actually learning grammar in her literacy program, helped her speak better and she therefore felt more comfortable to ask questions in health care interactions.

Because she was learning to read, Lynn felt that she was “starting to learn, and get a little bit of everything, so I would like to get a little bit of everything [health information],” including videos and pamphlets to help her understand her skin problem. Since returning to school, she believed that she expressed herself better than before and that had positively affected her health. Additionally, she had learned specific health information at school, such as healthy food choices. Learning to read allowed her to successfully search out and read more information about her health. As stated by Lynn:

when you go to grocery let's say something you don't have to eat or something. But if you can read, you'll be able to see what is in there. Like now I'll be able to read like labels [on food cans], everything it help a lot.

Abeba felt that she was healthier and she felt better because her ability to read and write had improved since going back to school. Abeba believed that these improved abilities helped her control her arthritis because “I read many [health] book. I talk with the people [in health care]. And that time I understand what they say, why I am asking them.”

Cognitive Apprenticeships

Situated cognition's concept of cognitive apprenticeships, in which individuals learn as a result of modeling, mentoring, coaching, scaffolding, and experiential learning (Wenger, 1998), can be used to explain how the participants learned new knowledge, skills, and behaviour from both their peers in the class and literacy instructors. Since returning to school Louise thinks,

I understand more because the fact is I wouldn't ask questions before. Because I just felt that she [the doctor] knows better than me. Why should I ask questions? But now that I have come back to school, to find out things you have to ask questions.

The participants then used these new or improved abilities in the health care environment to improve their ability to cope with their chronic illness and deal with the healthcare system. Participants were aware of how their improved literacy ability had actually affected their health status. Carolyn thought that “if I wouldn’t have gone back to school some of the vocabulary [in health care interactions] that they use now I probably wouldn’t even understand.”

Situated Learning

Within situated learning are the practical components of the situated cognition theory. The four elements of situated learning are content, context, community, and participation (Stein, 1998). All of these elements were represented in the learning experiences of the participants.

The element of content in situated learning includes the facts and processes of the task. For the participants in this study, their patient education experiences included learning about their condition, recognition of signs and symptoms of their chronic illness, and applying self-management strategies. For example, the participants learned when and how to take medications that were prescribed to help them control symptoms. Nyela had to learn how to take her blood sugar level to help control her diabetes on a daily basis. This involved Nyela learning, from the nurse, how to prick her finger, place a drop of blood on a small strip of paper, and place the paper into a small machine called a blood glucose meter or glucometer. The meter would indicate numerically her blood sugar level at that point of time.

Using this number, Nyela would make decisions on how much and what she should eat to maintain her blood sugar level within a healthy range. Nyela felt that she had good instruction and was able to do the physical tasks of taking her blood glucose level and make decisions based on the number on the glucometer. Her family doctor also monitored her blood glucose level every three months.

Unfortunately, not all of the necessary *content* of instruction was always provided. For example, Monique related that when she was given her “puffer” to use for her asthma, she was just told by her doctor “to use that” without being told how to use it. She “had to learn to use it the hard way when she was in the hospital because of her asthma.”

The context of the learning experience is just as important as the content. Context includes the situations, values, beliefs, and environmental cues of the learning activity. Within this study, participants had patient education experiences in a variety of settings including doctors’ offices, pharmacies, emergency rooms, hospitals, community health centres, their literacy classrooms, and their own homes.

Participants received patient education at a time when their chronic illness was stable, and at times when they were experiencing a health crisis. All of the participants, except Ramon, felt that they learned best when they are actually sick, during a health crisis, or an exacerbation of their chronic illness. They felt that they listened better at these times. Nyela mentioned that she took more notice of the information. Warda felt that it was better “when a person is sick, you find more what is wrong, his situation, you know, when I am healthy I don't want to see a doctor.” Sonia stated that she listened more after a health crisis to the doctor's advice:

because you really want, ... you really want you know to get well. But after you actually had that [advice]. And you did what he told you and you realize, if I had paid attention and done what he said I won't be, you know, I won't have the attack.

Community, as defined within situated cognition, is the group of people with whom the learner negotiates and creates meaning. Through community, learners interpret, reflect upon, and form meaning according to common understanding. It appeared that the primary, most significant community of practice for the participants consisted of their classmates and instructor in their literacy program. Participation occurs in the community of practice. Participation is the process whereby learners work with instructors and peers to solve problems related to daily living (Kirshner & Whitson, 1997). This process includes the interchange of ideas and requires dialogue with members of the learning community.

It was surprising to note that none of the participants had belonged to a community of other people with the same chronic illness, such as an arthritis support group, or indeed any health related group. The literacy classroom was a community in which participants learned not only literacy skills; they also learned social skills to help them deal with their chronic illnesses and interact with the health care system. This occurred in the literacy classes through both formal discussions about health issues as well in informal discussions. For example, Abeba mentioned that she valued coming back to school to improve her English, but she also appreciated the opportunity to make friends at school. She felt that these friends have been able to help her understand her health and deal with the health care system. Louise's participation in the literacy classroom provided her with the opportunity to meet other adults with limited literacy and to develop a sense of belonging, which she felt gave her more confidence in health care interactions.

The other community of practice in which the majority of participants were members was their households. These communities included their spouses and their children, who acted in the roles of educator and translator for some participants. All of the participants mentioned that they reflected on what they were told by health care professionals, and then thought about it at home and talked to their spouses or children about the information. When they were at home, Warda, Nigist, and Abeba asked their children about unfamiliar words that the doctor had used in an interaction earlier in the day. Nyela, Monique, and Mekal all preferred to go to their doctor's appointment with their spouses, so at home they were able to further discuss with them what occurred during the health care interaction. Lynn found that she learned both in the doctor's office and at home; she noted that "you have to listen and learn something so when you come to your home you're all alone, so you have to think again and learn again."

Only three of the participants had had patient education experiences with a group of people who also had the same chronic illness. Nyela had attended free workshops about diabetes and cancer at the community health centre. She had diabetes and found these workshops helpful. Sonia had attended patient education sessions on asthma as a child in Portugal. Nasreen had also attended sessions about diabetes at the community health centre, as well as education sessions, not specifically for people with diabetes, on general topics such as diet and exercise. She found these sessions very useful and stated that she was always asking the coordinator of the centre which sessions would be offered in the future, so she could learn more about her health. Although they attended these sessions, the participants mentioned that they did not feel comfortable asking questions, and did not interact with others who attended the sessions before upgrading their literacy abilities.

These situations demonstrate that the participants felt that the sessions were helpful to them but they did not feel comfortable engaging in a dialogue with the instructor or the other learners. This may indicate that for them, the health care system's imposed communities do not always provide the best learning opportunities for individuals with limited literacy. In these types of educational sessions there was limited or no negotiation of learning for the participants. Therefore, these experiences were not seen as true communities of practice.

Interesting though, all of the participants stated when asked if they prefer learning alone or in a group, that a group setting was preferred. All of the participants thought group sessions would be, or had been, helpful because they could talk to others about their problems and learn from each other. According to the participants, the greatest benefit of group learning is to learn from others, hear others' stories and other people's opinions. The participants also felt that the group sessions allowed them to meet new people. Carolyn thought that the social aspect of a group setting would be helpful because:

you can get, I don't know, I am a social person. So I mean, to talk to, to sit there, and have a certain amount time. Maybe with other people like a group discussion would help because I have an idea that this person doesn't even think of. But it could help them, you know or they have vice-a-versa [an idea]. I think it would be good if we could have a group discussion.

Nigist also felt that it would be helpful to learn in a group session because "sharing different ideas maybe, I don't know, something that they know maybe I know something that they don't know, share ideas, learning."

Notably, one individual had reservations about group settings for patient education. Louise expressed that she had recently been to the hospital to attend a group education session on nutrition. She would have preferred to have this education on a one-to-one basis;

Louise stated that she was a very private person and she did not like to share her health problems with others.

Situated cognition helped to illuminate the unique learning experiences for the participants. This theory also highlights the crucial role that the context, situation, anchored instruction, cognitive apprenticeships, and the community of practice hold for the participants. A surprising finding of this study was that the primary community of practice for the participants was their literacy classrooms and not a health care group. Through the participants' involvement in their classroom community of practice, their literacy abilities improved, which in turn helped them in overcoming some of the barriers that they faced in their patient education experiences. The following section will highlight the system barriers that the participants were required to overcome during their patient education experiences.

Critical Theory

Within critical theory exists societal power that informs the context and process of learning. The system has the power to prevent and block the learner from learning (Welton, 1995b). Learners must overcome power-related obstacles to achieve full learning potential and active participation in society. The key concepts of critical theory are reflective discourse, institutions as learning communities, and the interplay of the lifeworld and the system (Welton, 1993). In critical theory, individuals take meaning from an experience, as opposed to giving meaning to an experience in transformational learning theory, and learning within an experience in situated cognition theory.

In critical theory, analysis learner characteristics, such as having limited literacy skills, are seen as a systemic social problem, rather than an individual's problem. According to Vygotsky (1978) "an individual's development and social and cultural change, occurs through the individual's linguistically mediated internalization and subsequent

externalization of the goals and processes of action and interaction of these activities" (p. 67). For the participants, some of these linguistically mediated goals and processes were limited in terms of the conceptualization of health and illness due to their lack of medical vocabulary. Such limitations hinder the ability of the patient to engage in reflective discourse. This is not surprising given the medicalization of illness (Foucault, 1973) or the tendency of medical personnel in positions of power to describe illness in terms that only they can understand. This limits people's abilities to control their own health without the help of the perceived powerful health care professionals.

Reflective Discourse

The participants were very much aware of their responsibility for their own health, but feelings of powerlessness were often barriers to taking this role. As noted earlier, the participants' health learning communities were actually the literacy classroom and these communities were comprised of the participants' instructors and peers, other individuals without formal healthcare training. The health care system posed many barriers for the participants and was not viewed as a learning community. The system incorporates and maintains a power imbalance between patients and providers. The participants recognized this imbalance of power in their dealings within the healthcare system.

The participants' patient education experiences often left them feeling powerless and marginalized, resulting in them feeling voiceless in the system. This is indeed not a feeling that only the participants in this study experienced. In fact, Welton (2005) believes many in society also have "loss of meaning, feelings of powerlessness, unhappiness in the midst of a glut of material possessions, despair over deepening discrepancies between rich and poor, social fragmentation, moral confusion" (p. 180). For the participants, however, their sense of powerlessness actually altered as their meaning perspectives shifted.

Critical theory's emphasis on larger system issues of power and knowledge lends itself to the issue of literacy and health. Critical theory suggests that we are tied to our own identity by a conscience and by self-knowledge, both of which were constructed for us with through practices of power (Pearson & Podeschi, 1999). It is well recognized that there is an imbalance of power between healthcare professionals and patients during healthcare interactions (Hydén & Mishler, 1999). Such an imbalance of power, noted by the participants, seems to stem from society's belief regarding the production and treatment of illness. Furthermore, this imbalance of power appears to allow health care professionals to "promulgate a biomedical model of disease and to simultaneously undermine patient's own experience and understanding" (Maynard, 1991, p. 448). Hydén and Mishler (1999) suggest that this pervasive asymmetry of power has three components. The components are: "structural, macro-social factors, conflicts between patients' lived experiences of their problems and medical conception of illness; and cultural expectations, shared by both physician and patients, about their respective roles in this institutionalized context" (pp. 177-8). The macro-social factors are similar to the critical theory concepts of institutions as learning communities and the interplay of the lifeworld and the system. The conflict between patients' lived experiences and medical conception of illness contains elements of reflective discourse and the interplay of the lifeworld and the system. The cultural expectations about roles in institutionalized context are close to the critical theory concept of institutions as learning communities.

Interplay of the Lifeworld and the System

The interplay of the lifeworld and the system for the participants was characterized by the fact that they were living with both limited literacy and chronic illnesses; two situations that required the participants to interact with two different systems, the education

system and the health care system. Each of the two systems seems to expect that people fit into only their single system. This is related to Lemke's (1995) view that "social systems are systems of doings, not of beings as such" (p. 103). The education system did not take into consideration the participants' chronic illnesses and how these might affect learning. Related pain, fatigue, and treatment side effects can all lead to problems with concentration. Ramon felt that due to his chronic pain, it was difficult to sit for long periods of time in the classroom. Warda unfortunately had to leave her literacy program due to her arthritis as she was also unable to sit for long periods of time. As well, having a chronic illness is likely to affect a person's ability to attend classes when one must schedule medical appointments and tests around school hours. That was the case for the majority of the participants; they had to miss some school because the only time they could get a doctor's appointment was during school hours. They had to accept the appointment times offered, especially if it was for a visit with a specialist. If they did not take the appointment offered, they would have to wait months before another appointment could be scheduled.

Similarly, the health care system did not appear to take into consideration the participants' limited literacy. The dilemma for the participants is that they all recognized that they were responsible for managing their own health, but they also felt that many times they did not receive information that they could understand and use, or they did not receive the information they needed. Participants acknowledged health providers' time limitations and adjusted their behaviour accordingly. They did not ask for information because they did not want to take too much time from others who were waiting to see the health care professional. If the doctor asked them if they understood or had any questions, and the participant felt that there was not enough time, then they said that they understood things, and they had no questions. This is a concern because health care professionals may make assumptions that

the patient already understands the nature of his or her disease and therefore not provide any information (London, 1997). Even if the patient was provided with information, there appeared to be an assumption on the part of the health care providers that the participants had the skill level to make informed appropriate choices. If the patient does not ask any questions, this further supports these assumptions.

The health care system, and the health care professionals representing the system, did not help the participants feel comfortable or confident. The system did not take into consideration the unique challenges that the participants faced. This is partly due to the fact that many health care professionals are not aware of the number of patients living with limited literacy. As well, the participants did not feel comfortable enough to share with their health care providers that they had limited literacy. This resulted in a barrier for the participants to receive patient education. Unfortunately, there were other barriers noted as well in each of the themes. Examples of specific barriers are described below according to their related themes.

Barriers within the theme of different roles and relationships related to characteristics of the health care system, such as the lack of translators within health care facilities, and necessitating participants' reliance on family and friends, who may have their own language and literacy limitations. Reliance on family members also resulted in role reversal for many in terms of the parent-child relationship; as participants' literacy abilities improved, they were able to regain their traditional role as parent and caregiver.

Within the language and health interactions theme, barriers included the use of written information that was not useful to the participants because of difficulty with the vocabulary used. These difficulties could arise because of the use of medical terms, the level of reading required, or the language of the material not being in the primary language of the

participants. Also, often written information did not discuss issues that were most important to the patients. Within verbal interactions, barriers occurred due to unfamiliarity with the medical discourse used by health care professionals.

Participants expressed that they felt that they were living between worlds. Many participants articulated feelings of general social isolation. Barriers within the mismatched expectations theme concern the differences in expectations between what information health providers felt the participants needed, and what information participants themselves felt they needed and hoped to obtain from the health care provider. Often the information participants were given was not precise enough to allow for the formulation of a concrete and individualized plan. For example, participants who had diabetes were told to exercise more, but were not given specific information about what types of exercise to do. Within the larger health care system, time presented a major barrier. Participants noted that there was not enough time in patient-provider encounters to build trust and exchange information. Participants expressed feelings of powerlessness in interacting with health care providers, including feelings of fear of exposure of being discovered as having limited literacy.

These barriers were lessened for the participants due to their participation in a literacy classroom, their community of practice. This participation resulted in their literacy abilities improving, which in turn prepared the participants to interact with the health care system more effectively. For example, Mekal felt that he understood more because he felt that his listening skills had improved. He thought that he paid more attention: "I do not tune out as much, I seem to be able to focus better." This improved attention may be a result of both improved literacy ability, as well as an increased capacity to attend to a teacher as a result of further classroom experience. Addie, since returning to school, found "that I understand better." Addie also perceived that learning to read, write, listen, and talk better had affected

her health significantly. She could read some of the paperwork that she had to sign and she found that she was more inquisitive. She stated that “I um never found myself very much to ask questions, but I find that since I’ve started school I’m more, I’m asking more questions and ah and being able to answer questions better.”

The process of filling out health forms for the participants is often the beginning of their entry into the health care system. These forms are used in health care as a prescreening type of assessment that every patient must complete before going in to see a healthcare professional either in an office, clinic, or even in a hospital setting. The expectation is that the patient can fill the forms out accurately, and time will be saved because the healthcare professionals can obtain the information without taking time during an interview to ask. These forms are used to gather very important information including which medications the person is taking, what surgeries they have had, or if the person has allergies. While the information on these forms tended to be verified by health care staff in the past, increasingly the information is accepted as is. Participants had previously developed strategies to cope when faced with this very specific task of filling out health forms.

Louise mentioned that she looked for someone nice who could help her fill out forms. Someone nice “was someone who smiled a lot and appeared to get along with others.” Nigist’s strategy was to take the form home to fill out with her children’s help. Some of the participants mentioned that they either had the secretary help them or they did not fill the forms out. When they went into the room to see the doctor, they would be directly asked the questions that were on the form. All the participants mentioned that, after returning to school, they could fill out the forms independently due to their improved abilities to read and write.

Participants' improvement in literacy ability also improved their ability to control their health. Mekal mentioned that after going back to school, he was able to read any book, talk to people, understand things, and share things with them. Mekal realized that

being able to read has really, really affected it [my health] simply because they give you pamphlets with pictures in it, it is all words. And I am sitting in the doctor's office you have a 20 minute wait. There are magazines or there are different pamphlets there that you can pick up and read. I will pick up a pamphlet rather than a magazine and read about what's going on [with my health] and try to figure out what. Before I wasn't able to sit down and pick up a pamphlet and actually read it. I could pick up the pamphlet. I would look at it and put it back but now I can sit down and read it and it makes a big difference [to my health].

Abeba also felt that learning how to read, write, speak, and listen better had helped her control her arthritis.

All of the participants felt that if their literacy skills included such things as reading, writing, listening, and talking were even better, it would make it easier to deal with the healthcare system and their comprehension would be improved so that they would have more control over their health. There was a feeling of hope that their literacy would improve and as a result, their health status.

Mekal stated that if his writing skills were even better, he would ask more questions after filling out a questionnaire at the hospital or the doctor's office. Lynn thought that if she could read and write even better than she could, she would be better able to pick up pamphlets and read about her health. "For example, read about breast self-examination, if you can not read, you would not be aware that you should check your breasts." Nigist

thought her health would be improved if she could read and write even better than she could now.

The participation in the learning community of the literacy classroom and the resultant skill development encouraged participants to critically reflect and redefine themselves as competent adults who had the right to ask questions and the ability to look for information to manage their health problem.

Conclusions

Within Chapter 5, the findings of the study were situated in the current body of literature in the key fields of literacy and health, patient education and chronic illness, and adult learning theories to provide a structural description of the phenomenon. Many of the themes have been noted previously in the literacy and health qualitative research, as well as in the patient education and chronic illness literature, and these similarities were discussed. In addition, the findings were placed within the adult learning theories of transformational learning theory, situated cognition, and critical theory.

CHAPTER SIX- SUMMARY AND DISCUSSION

This chapter will begin with a summary of the study findings in relation to the research questions using a visual representation. Then the contributions of this study in the areas of theory, practice, and policy will be discussed. Finally, limitations of the study, recommended future research, and concluding thoughts will be presented.

Summary of the Study

The purpose of this study was to uncover the meaning of patient education experiences for adults with limited literacy and chronic illness. The overarching question guiding this inquiry was: What is the meaning of patient education experiences for adults with limited literacy and chronic illness? The two secondary questions were: 1) How do patient education experiences affect adults with limited literacy and chronic illness? and 2) What are the barriers that adults with limited literacy and chronic illness encounter in patient education experiences?

The meaning or essence of the experiences for the participants is best described using the five themes of different roles and relationships, living between worlds, language in health care interactions, mismatched expectations, and powerlessness. It appears that the meaning of the patient education experiences for the participants was one of a shifting towards perspective transformation. Their perspective shifted from powerlessness, dependence, isolation, not having expectations met and not understanding the language, to one of having some power, some independence, some fellowship, some ability to have expectations met, and some ability to learn and understand the language of healthcare.

With regards to the secondary question, “How do patient education experiences affect adults with limited literacy and a chronic illness?” it appears that the patient education, in the form of provision of a diagnosis, set in place the process of perspective transformation.

Through this community of practice, participants were able to overcome some of the barriers or at least to lessen the barriers and to take control over their lives, so that they could manage their chronic illnesses better. For example, the participants' ability to read improved through the literacy classroom instruction and resulted in their being able to find health information on their own.

In terms of the second question, the barriers included difficulties obtaining or understanding patient education information geared towards helping them manage their chronic illnesses. As the participants' literacy abilities and self-efficacy improved through their community of practice, these barriers were reduced. None of the barriers completely disappeared or were removed for the participants because these barriers were part of, or reinforced by, the health care system.

The three components of the essence of patient education experiences for the participants are illustrated in Figure 1. These components are the individual learner, the learning context, and the system. The five themes that emerged from the data are found in the individual learner component. The next component of the visual representation is the learning context. This is the community of practice that is the students and instructors in the literacy classrooms. Through participating in this community of practice which allowed them to enhance their literacy abilities, the participants began the process of perspective transformation. The arrows joining the learning context with the system are the different avenues of patient education experiences. The dotted line represents the barriers within the system that the participants had to break through to access the patient education experiences. The system component is divided into the primary sources of patient education experiences for the participants. These sources were their family doctor, their pharmacist, friends and family and the participants themselves.

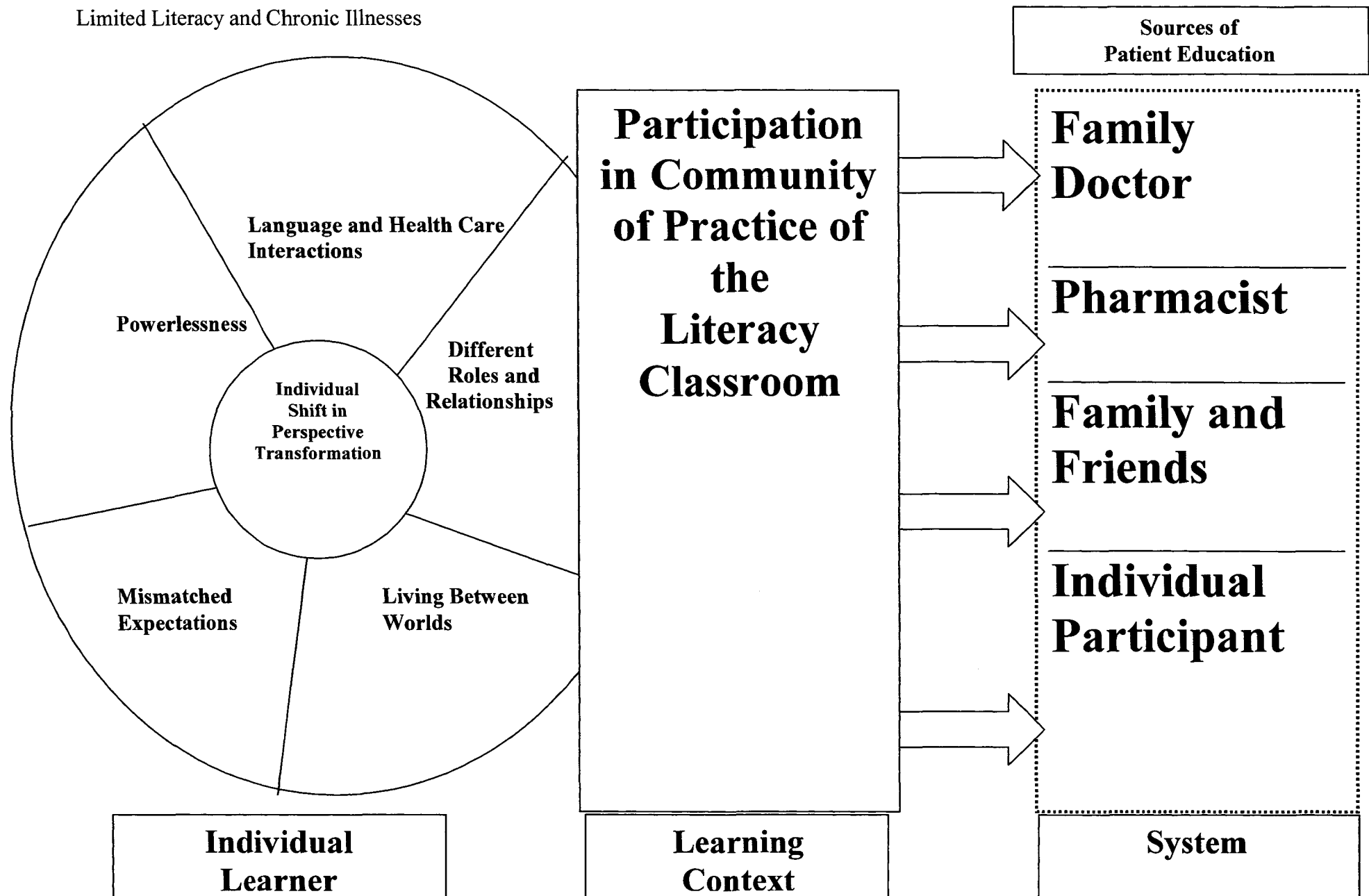


Figure 1:
Visual representation of the meaning of patient education experiences for adults living with limited literacy and chronic illnesses

The purpose of this study was to uncover the meaning of the patient education experiences for adults living with limited literacy and chronic illnesses. It appears that this meaning is one of a shift of meaning perspectives. These perspectives are based on the participants' values, beliefs, expectations, and feelings about the chronic illness. For the participants in this study, their illness perspectives were formed before they entered the literacy classrooms.

These meaning perspectives, however, were altered for the participants in this study as a result of participating in a community of practice, their literacy classrooms. While the educational experience of hearing the diagnosis began the process of alteration of meaning perspectives, the learning process that occurred in the classrooms was a catalyst for the individual participants to begin to become more fully engaged in patient education experiences. This enhanced engagement allowed them to learn to manage their chronic illnesses. Although the participants continued to face the same previously routinely encountered systemic barriers to access patient education, how the participants saw and interacted with these barriers changed due to the participants' shifts in perspective about their chronic illness and their limited literacy.

The literacy classroom experiences, their participation within this community of practice, enabled the participants to start to overcome these barriers. The findings from this study contribute to theory, practice, and policy in the area of literacy and health. The contributions to theory will be explored in the next section.

Contributions to Theory

The findings of this study have demonstrated that adults with limited literacy and chronic illnesses have unique challenges and barriers to learning in patient education

experiences. Using the lens of transformational learning, it was observed that the participants, as individual learners, had many schemes and perspectives about their chronic illnesses. Situated cognition helped explain how their literacy classrooms were the key context where learning occurred, and that this learning occurred within a community of practice. Finally, critical theory revealed the systemic barriers that the participants faced in accessing patient education experiences.

This study further demonstrated that transformational learning theory is a helpful lens through which to view the unique learning experiences of adult dealing with patient education. Using the 10 phases of transformational learning to describe the participants' experience helped illuminate the phases in which the process of perspective transformation occurs, during patient education geared towards management of chronic illnesses. Other researchers have noted the importance of these perspectives. Paterson (2003) states, for example, that a person living with chronic illness has "a preferred perspective, one that he or she assumes most often in his or her experience of living with chronic illness" (p. 988). Transformational learning theory has been previously demonstrated to be a useful framework for understanding patient education experiences for adults with chronic illnesses (Ashe et al., 2005; Carpenter, 1994; Dubouloz, Laporte, Hall, Ashe, & Smith, 2004).

Carpenter (1994) used both phenomenology and transformational learning for her study. Within this study, three themes emerged: rediscovering self, redefining disability, and establishing a new identity. She concluded that the participants' spinal cord injury was the disorientating dilemma which resulted in perspective transformation.

Dubouloz, Chevrier and Savoie- Zajc (2001) studied the patient education experiences for a group of nine patients following a heart attack. They found that, in trying to establish a new occupational balance in their lives, the participants had to “deconstruct and reconstruct old meaning perspectives related to work, self-care, rest and sleep” (p. 171). In further study, Dubouloz and colleagues (2004) investigated the transformation of meaning perspectives in clients with rheumatoid arthritis during home-based rehabilitation. A grounded theory approach was used to collect data from five adult clients. The six themes that emerged were illness, independence, activity, altruism, self-caring, and self-respect. The authors concluded that deconstruction and reconstruction of meaning perspectives occurred for the clients as well. The clients learned behaviors and knowledge, through occupational therapy, that helped them transform meaning perspective (p. 398).

Similarly, in a related study examining the process of change among adults in arthritis health education groups, Ashe and colleagues (2005) noted that the client’s process of change in meaning perspectives could lead to health-promoting behaviors and positive health outcomes. These health outcomes not only were desired by the patients, but were seen as important indicators of effective chronic illness management as defined by the health care provider.

Mezirow (1997) suggests that symbols and language provide a person’s frame of reference. Individuals must rely on familiar ways of thinking, being, and understanding as a way of interpreting the new experience. He also thinks that a key vehicle to learning involves communication; therefore learning is affected by things such as language mastery and the self-image of the learner. Through the involvement in the literacy

classroom, it appeared that the participants also improved in self-efficacy. Through this investigation, these issues surrounding language were certainly at the foreground for the participants.

Similarly to transformative learning, situated cognition theory was also useful in highlighting a significant facilitator of the patient education experiences of the participants. The findings of the current study reinforce previous findings in literacy research in which the literacy classroom was identified as a fundamental community of practice for individuals with limited literacy. The unique contribution to our understanding of literacy communities of practice made by the current study is the identification of the essential role these groups play in the improving and maintaining the *health* of members.

In a recent review of the field of adult literacy in Canada, Quigley, Folinsbee, and Kraglund-Gauthier (2006) noted that, in the area of Health Literacy, there were studies that had investigated issues of barriers to health for people with limited literacy but little examination of the health care systemic issues. The current study contributes to the literature through uncovering some of these systemic issues, through use of critical theory.

Critical theory explains the issues of power within a person's lifeworld. People with chronic illnesses, must make meaning within these lifeworld contexts (Hydén & Mishler, 1999). Although many people believe that the "dominant discourse of medicine is undergoing radical change, invaded by new definitions and theories of health and illness" (Hydén & Mishler, 1999, p. 185), it has not yet embraced the issues of people living with limited literacy. Certainly health care professionals do not consciously set out

to oppress such individuals, but the system that is in place contributes to this happening by maintaining power differentials. This power relationship was also described by Foucault (1973) as the capacity of social structures such as schools and hospitals to maintain power by ensuring discipline among the many people in society.

Lack of time for interaction between patients and health care providers is a major system level factor that contributes to the oppression of individuals with limited literacy and chronic illnesses. As noted above, it has been demonstrated in the current and previous studies that meaning perspectives must shift before individuals become able to manage their health in the face of chronic illness. Time is needed for the learner to go through this process, which may require weeks or months. Time is severely limited in the health care system; single encounters may be brief and repeated encounters may be discouraged. Renewed emphasis on primary health care supports the role of the family doctor as a primary patient educator. As this physician ideally has a long term relationship with the patient, this would be supportive of assisting individuals in the process of shifting meaning perspectives.

Implications for Practice

Within this section of the chapter are the implications of the findings from this study for practice in the area of health care and literacy. The findings are presented as well as specific suggestions that the participants made during the interviews that were directed towards health care and literacy practitioners.

Health Care Practice

Implications for health care practice include the use of transformational learning theory to understand patient change necessary to managing health, issues related to

communication, and lessons from the lived experience of individuals with limited literacy and chronic illness.

Health care providers would benefit from a greater understanding of transformational learning theory and the process of meaning perspective transformation (Dubouloz et al., 2004). The current study points out that such transformation occurs in a community of practice. However, group patient education experiences may not always provide such a community for individuals with limited literacy. Health care providers need to be sensitive to the issues that such learners may face in chronic illness support-type groups, and ensure the provision of a safe atmosphere and the opportunity for one-to-one education where necessary.

Within the Carpenter's study (1994), the participants had developed a three-phased process of transformation "rediscovering, redefining and establishing." This abridged version of the 10 phase process from Mezirow could be a useful tool to health care providers when providing patient education. As well as the phases, Mezirow (2000) has also recognized that there are learning conditions or environments that are more conducive to learning. These include places in which there is "a sense of safety, openness, and trust" for the learner (p. 312).

Effective communication between patient and professional is critical to optimizing quality of care and reducing complications due to misunderstanding. There is a growing realization that health care professionals require not only medical knowledge and skills; they also need excellent communication skills to be effective clinicians. This has resulted in an increasing emphasis on communication skills in the curricula of health professional preparation programs (Foxman, 2006).

We need to look at health care communication as a shared responsibility, as Osborne (2002), an occupational therapist working in the area of health literacy, proposes. In her view, communication is a two-way street; it is as important that the provider understands the patient as it is that the patient understands the provider. The study demonstrated the importance of the provider understanding the patient's meaning schema. An understanding of the patient's meaning schema seemed to be particularly important in discerning what information patients needed, while guarding against the tendency to view certain ways of looking at health and illness "common knowledge."

Over the last ten years, the role of the health care professional has shifted from "wise healer, to expert advisor/teacher, and finally emerged as facilitator of change" (Glanville, 2000, p. 59). As a result of health care reform, Canadians are being encouraged to take more responsibility for their own health (Romanow, 2002). The role of the health professional in patient education, therefore, has moved from one of imparting information to empowering patients to use their own resources to help themselves (Glanville, 2000).

The current study demonstrated that prior to their involvement in literacy programs, the participants were not able to mobilize resources to improve and maintain their health. Given these results, it is not surprising that other research has demonstrated that self-management skills are poorest among patients with limited literacy skills (Williams, Baker, Honig, Lee, & Nowlan, 1998). This is a finding with serious implications for patients with low literacy skills. Further pressure on patients to manage their own health will be particularly detrimental to individuals with low literacy, particularly those living outside of communities of practice such as health literacy

programs. The use of a “banking concept” when providing education as noted by Freire (1970), in which the instructor deposits knowledge into students expecting them to file it for later use is unlikely to be helpful to individuals with low literacy.

In terms of health care practice, it is important for health care professionals to understand the lived experiences of patients dealing with limited literacy and chronic illnesses. This is especially important in light of the recent statistics from the Adult Literacy and Life Skill Survey (Statistics Canada & Organisation for Economic Co-operation and Development, 2005) which indicate that, due to the high prevalence literacy limitations, all health care providers are likely to interact with at least some individuals with limited literacy among the patients they treat. The findings of this study highlight the need to increase the awareness of health care professionals of the impact of limited literacy on patient education experiences. This increased awareness hopefully will result in an environment where people would feel comfortable to disclose that they have limited literacy to their health care provider. This, in turn, would lead to a more beneficial patient education experiences for both the patient and the provider.

More specifically, all participants mentioned that the vocabulary used in health care interactions often excludes and does not engage patients. These findings point out the importance of Lemke’s (1995) advice “that by examining the texts of our own community we can come to understand how and why we make the meanings we do, and what other meanings might be made instead” (p. 70). Health care providers would do well to pay close attention to the language used in patient education encounters. They may be inadvertently excluding patients. Even using the term patient education may exclude patients. As noted previously, none of the participants had heard of the term

patient education. It could be possible that hospitals place signs up for an upcoming “patient education session” on diabetes and patients do not attend because they do not know what patient education is and do not understand the sign.

Unfortunately, it seems that some of patient education information that participants received was in a written format, which is clearly not the best format for people who have limited literacy. To offset this heavy reliance on written material, participants suggested that health care professionals should also use models, diagrams, and pictures when explaining things to patients. Participants found that when their family doctor used pictures, props, and other models in his or her office to explain things and that it was very helpful.

In verbal instruction, unfamiliar vocabulary and speed of the delivery of the information often presented barriers to learning for the participants. They suggested that health care professionals use short words, speak more slowly, and make people feel comfortable in asking questions. They also recommended that the health care provider ensures that patients have understood what they have been told by saying things like, “Can you repeat that back to me, so I can see that you understand what I just told you?” Not surprisingly, participants in the current study expressed their wish for health care providers to use common words, not medical terms. As many participants stated, they are not doctors, so how could they be expected to understand medical terms. As well, health care professionals need to create a safe environment where the patients would feel comfortable disclosing that they had limited literacy.

Many participants suggested that paid or volunteer translators be available during

health professional visits when the patient is less comfortable in the language of the health care provider. This person could be a friend, family member, or even someone from the government. The Gillis and Quigley (2004) study took this one step further by noting the participants recommendation for what they termed, “client advocates,” who would “help people move through the health care system and to interpret when English is not the first language” (p. 33).

Participants also suggested that health care professionals could do a better job providing patient education to people with limited literacy and a chronic illness by taking more time to explain things in detail and to help people integrate this new information into their daily lives. When asked how much time would be enough time for a doctor’s appointment, all the participants suggested 20 to 30 minutes. This is the timeframe participants believed would be sufficient for the doctor to complete the physical exam and that would allow for any questions that they had for the doctor.

Participants suggested that health care professionals try several different learning approaches, methods, and styles with a person, including visual material with props or pictures, verbal instruction and a written pamphlet or handout. It was very evident that the participants had determined their own optimal learning methods after frustrating and difficult experiences, and were eager that health care providers could accommodate these through different teaching methods and media. Due to the participants feeling of powerlessness, however, they did not feel comfortable in sharing this with their health care providers.

Regardless of the delivery method, participants thought that health care professionals must check patients’ understanding of health information and advice

through follow up questions at later appointments. Participants emphasized that such education and follow-up must be delivered using a non-threatening and nonjudgmental approach.

These recommendations that are based on the findings of the current study reinforce those of participants in the Canadian Public Health Association's second Canadian Conference on Literacy and Health. At that conference, specific strategies were used to give voice to Canadians living with limited literacy. Their personal stories, their expertise, and their views about dealing with the health care system, were recorded through focused workshops conducted in French and English (Canadian Public Health Association, 2005). As well, there was a Learners Gallery which showcased the participants' stories, art, and poetry based on their experience with health and the challenges and barriers that they encountered (Canadian Public Health Association, 2005). Suggestions included using simple words, talking slowly, using both oral and written information, showing respect, including pictures and videos, having the patient attend appointments with someone else, and telephoning in a week's time to check up on the patient. Conference participants also recommended having learners come to speak to health care students, using videos in waiting rooms, and slowing down to build trust (Canadian Public Health Association, 2005).

To help change health care practice, health care professionals need to be provided with the knowledge, skills, and behavioural competencies to help optimize patient education experiences for patients with limited literacy. These competencies, such as using a variety of teaching methods, not just verbal instruction when explaining things, could be under the larger topic area of health care communication. Communication is a

key foundational skill for all health care providers (Maguire & Pitceathly, 2002). Therefore, it would make the most sense to target training in this area through an interprofessional educational framework.

In recent years, Health Canada has adopted the use of D'Amour and Oandasan's (2004) model of "Interprofessional Education for Collaborative Patient Centred Practice" as a method to focus research and practice initiatives. Using this model, a training program could be designed in which health care communication including the specific issues of literacy and health could be used. This would mean that health care providers would learn about these issues together, working in a team environment. A logical choice would be in the area of chronic disease management, in which many health care providers may be seeing the patient together. The idea would not only target practicing health care providers, but also students in health care programs. The competencies could be taught in the health care programs again using an interprofessional educational framework; use small groups learning and have adults living with limited literacy and a health problem come to talk to the students. This is in keeping with one of the emerging issues recognized by participants in a recent international conference that looked at ways to involve patients' voices in health professional education. The conference was entitled "Where's the Patient's Voice in Health Professional Education?" At that conference, the use of language and the power of language were identified as an important topic that needs to be included in health care professional curriculum (Farrell, Towle, & Godolphin, 2006). Again, with more health care providers aware of the issues of limited literacy, more people will feel comfortable to tell their health care provider that they have limited

literacy. As well, health care providers would know about the best patient educational methods to help people with limited literacy.

Literacy Practice

In addition to the above implications for health care practice, the findings of the current study also have implications in the area of literacy practice. These implications are related to the intimate link between health and literacy.

One of the key findings of the current study was the participants' perception that improvement in their literacy abilities resulted in improvement in their health status. All of the participants recounted examples of being better able to search out and understand health education information as a result of developing greater confidence and literacy skills. Furthermore, they believed that these skills would continue to develop, and that this would lead to an even greater ability to manage their health. They also felt that as their literacy improved, it would be increasingly easier for them to understand and deal with the health care system and obtain appropriate care.

The literacy classroom was their community of practice. That students should learn about health in a literacy classroom would not come as a surprise to literacy practitioners who have observed their students' interest in health and health care issues. The literacy classroom is an important place; it is a safe place for the learners to learn about health and the skills needed to navigate the health care system. Literacy practitioners, though, may have challenges in obtaining appropriate health education resources for their students. It might be that literacy instructors need to work with health care providers and learners to find the resources that would be most helpful and needed from the learners' perspective. This was one of the suggestions from the participants in

the current study. Participants suggested that health care professionals, such as nurses, could come into their classes and talk about general health issues. As long as the health care professionals treat the participants as adults with respect, the participants felt that learners in the literacy classes would benefit from these interactions.

The participants in the Canadian Public Health Association's conference recommended that literacy instructors work with health workers to figure out ways to provide services to people with literacy challenges, especially appropriate screening questions about literacy in the health care system. Within the educational system, the participants in the Gillis and colleagues (2004) study also suggested that literacy practitioners and policy makers reduce the barriers to attend literacy programs for adults, such as providing more flexibility in terms of the hours of literacy programs.

The challenge becomes how can literacy and health care practitioners work together to assist individuals dealing with health and literacy issues to manage their own health and effectively deal with the health care system. Successful collaborations between health care professionals and adult literacy practitioners have already resulted in other research projects and workshops being offered that link health care professionals and literacy practitioners (Centre for Literacy of Quebec, 2001; Gillis, Quigley, & MacIsaac, 2005). One type of collaboration, which would be easy to implement, would be to ask participants in literacy programs to help with the pilot testing of patient education materials, such as pamphlets and videos. The learners could use their experience to review and suggest what information and in what format they find the most helpful. This plain language editing service could be linked with employment preparation component of most literacy programs. This type of collaboration, it would be hoped, would serve to

increase the awareness of the issues in literacy and health for the health care providers. These types of projects, research studies, and the current study could be used to inform the frameworks of future projects in literacy and health and will be further discussed in the future research section.

Implications for Policy

The third area of study implications relate to policy. Knowledge from the current study may be used to inform social and health policy development. As we have seen in Canada over the past decade, health is a dominant theme in social and political discourse. Findings from this study indicate system-level barriers to optimal health among individuals living with chronic illness and limited literacy. At present, literacy and health is not explicitly discussed in policy circles. However, issues of patient safety, plain language usage, and health care facility accreditation and chronic disease management are. This section will explore these issues and discuss governmental literacy policy and public accountability.

Patient safety has been increasingly emphasized in Canadian health policy discussion, with the goal of decreasing costs related to health care in general and those associated with litigation more specifically. A report on patient safety and health care errors in Canada noted that problematic communication was a contributor to adverse events (Baker et al., 2004). The link between patient-professional communication, quality of care and health outcomes has been made in numerous studies, and limited health literacy has been suggested as an important consideration by the Institute of Medicine (2004).

In the mid 1990's, there were a number of malpractice cases in British Columbia that were based on lack of communication. In one case, the patient charged that her obstetrician/gynecologist did not explain adequately that her sterilization procedure was irreversible. The judge ruled in favor of the patient and cited that the physician "breached his professional duty by choosing language that left the patient in doubt" (Gordon, 1996, p. 1152). Although none of the participants in the present study had reported such extreme negative health care experiences because of issues of communication, all had experienced less than optimal care due to communication problems.

The argument in favor of the use of plain language and clear verbal communication in health care interactions has been further strengthened in Canada as a result of changes to the Canadian Council on Health Services Accreditation standards. These standards are used to accredit all hospitals and many health care facilities in Canada. The standards state that "health information must be based on the clients and families' information needs, and that it must be easy to read and use" (Shohet, 2004, p. 76). It will be interesting to note if this national accreditation requirement results in changes at the practice level in terms of health care delivery.

The scope of patient safety is a broader concept which not only includes direct patient-provider interactions but also the surrounding issues of prevention of complications, which is a good fit with chronic disease management. The present study's results could also be used in the area of policy and practice in chronic disease prevention and management. As mentioned previously, there are federal (CDPAC) and provincial alliances (OCDPA) in place to look at how best to deliver and fund chronic disease programs. As the participants in this study noted, everyone's experience with their

chronic illness is unique. The challenge is in designing programs which will be able to be address the needs of individual patients experiences living with chronic illness who also are living with limited literacy. As well, as mentioned previously, the results of the IALSS revealed that larger proportion of immigrants have low literacy compared to citizens born in Canada (Statistics Canada & Organisation for Economic Co-operation and Development, 2005). Taking into consideration the results of the IALSS for all Canadians, it can be postulated that there are many Canadians living with chronic illness and limited literacy and that the present system may not be helping them. The participants in this study had attempted to learn about managing their chronic illness but had had barriers in place. The gap between the literacy demands of the system and the literacy abilities of the patients must be narrowed to improve both the effectiveness of the health care system and the quality of life of the patients.

As challenging as it is to influence health care policy, it is equally difficult to alter literacy-related policy due to the fact that, in Canada, there is not just one type of organization which produces literacy policy or provides literacy programs. The literacy dossier has been moved around in the federal government and in the provincial governments. Literacy programs are provided by both governmental and non-government organizations. Many in the literacy field have thought, including the Canadian Education Association (2004), that “literacy should not be seen as a policy issue in isolation, but as an integral component in all social, economic and cultural policy” (p. 6). Such an approach has its advantages when dealing with an issue that is multidimensional. However, the challenges involved in writing and implementing a coherent policy across multiple sectors are enormous.

The previous federal Liberal government's decision to change Human Resources Development Canada (HRDC) ministry to Human Resources and Skills Development Canada (HRSDC) ministry could be seen as a reflection of the emphasis put on training and skill acquisition needed in the 21st century. The new ministry, at the time of this study, focuses on a knowledge based economy which entails "an ever-increasing demand for a well-educated and skilled workforce in all parts of the economy and in all parts of the country" (Government of Canada, 2005, p. 7). The assumption is that overall increases in Canadians' skills and learning will result in innovation which will lead to increases in productivity and competitiveness on the world stage, an increased standard of living for Canadians, and increased quality of life, which will in turn lead to an increase in skills and learning (Government of Canada, 2005, p. 7). The new federal Conservative government has changed the department's name again; it is now Human Resource and Social Development Canada (HRSDC). Recently the federal government has combined the NLS with the Office of Learning Technologies (OLT), and the Learning Initiatives Program (LIP) to form the Adult Learning, Literacy and Essential Skills Program (ALLESPP). It will be interesting to see what role and influence literacy will have in any new policy initiatives within this larger program.

Recent literacy policy has been more linked with improving skills related to employment rather than knowledge related to health. It may be difficult to influence the policy makers in this climate to consider seriously the link between literacy and health demonstrated in the current study, where quality of life is related solely to employment skills. A cost-benefit analysis of literacy education programs that considers health care costs as an outcome could make this issue more relevant to policy makers by

demonstrating cost savings of literacy education. However, adult education and health are funded by different Ministries, and therefore there is no or limited interdepartmental ability at this point to do a cost-benefit analysis.

To influence policy directives related to literacy and health, there is a need to situate the issue within the current policy framework. Due to the fragmentation of stakeholders, it is difficult to determine where issues related to both literacy and health fall within the political or bureaucratic systems. I would suggest that the focus be placed on the political system at this point, since politicians initiate policy change in Canada. But should such change be health driven or education/literacy driven? Who should be responsible for spearheading literacy and health initiatives?

Sorting out the contributions of the various stakeholders was a huge challenge documented in the Gillis and Quigley's (2004) collaborative project that brought together literacy, health care, educational, and social service organizations. A lot of time was required to build relationships among the organizations involved before the project even got started. This relationship building included getting people to buy into the concept that both literacy and health issues were important to them and to their organizations.

In terms of policy, the question remains as to whether the issue of literacy and health is one of public accountability at the systems level, operational, strategic management at the organization/program level, health care at the patient-provider level, or education at the instructor-learner level? I would argue that it is an issue at all of these levels. Such thinking is consistent with a recent definition of health literacy from the Institute of Medicine of the National Academies in the United States (Institute of Medicine of the National Academies (IOM) (2004) which states that:

Health literacy is the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions. But they do this within a community and a system. Health literacy goes beyond the individual. It also depends upon the skills, preferences, and expectations of health information and care providers: our doctors; nurses; administrators; home health workers; the media; and many others (p. 5).

The findings of the current study bore out the involvement of each of these levels, and demonstrated challenges faced by participants at the individual patient-provider, health organization, and governmental systems level.

Limitations of the Study

There were a number of limitations to this study. These were related to sampling, the interview schedule, the lack of an elicitation of an explicit definition of health from the participants, and issues related to the fact that the interviews were carried out by a health professional.

With respect to sampling, because the participants were purposefully selected, they may not be representative of all adults living with limited literacy and chronic illnesses. For example, adults with limited literacy and a chronic illness who do not attend literacy programs may have very different experiences with patient education. Also, the participants volunteered to be interviewed. They may have been particularly motivated to talk about their experiences because of particularly good or bad patient education experiences.

Although I recruited participants from seven different classrooms and between two different programs, all had employment preparation as their primary mandate. This might have resulted in restriction of participation by, for example, age and gender. However, this did not appear to be the case. The participants ranged in age from 24 to 68 years and were both male and female. The participants were living with a variety of chronic illnesses and had had a variety of patient education experiences.

An interesting aspect of the sample was that the majority of participants had English as a second language. I had not anticipated this at the beginning of this study. I had assumed that I would interview primarily native English speakers. Although the participants spoke English as a second language, they all had been in Canada for at least 10 years and had interacted with the health care system. While “representativeness” is not a criterion used in qualitative research, it is interesting to note that these participants were highly representative of Canadians who interact with the health care system in a large urban community like the setting of this study.

Another potential limitation of the study related to the questions from the two interview schedules used for the two interviews. For example, did the questions allow me to delve into the participants’ experiences? Did I neglect to ask things that might have helped to uncover other aspects of their experiences? One of my assumptions at the beginning of the study was that the participants might be uncomfortable speaking about a private issue such as health care, so I had to make sure that there were a variety of probes for each of the main questions in the interview. I tried to balance the variety of experiences that I asked about. Mishler (1999) has cautioned qualitative researchers not to believe that “the story they hear in the particular contexts of their interviews is the one

‘true’ story” (p. 52). Rather, any interview represents the interviewees’ thoughts and reflections of experience in their lives from the perspective of that point in time.

Although I have interviewed people living with limited literacy before, I do not have a lot of experience with interviewing people living with limited literacy.

A further limitation was that participants were not asked what it meant to them to be healthy. They were not asked how they viewed being in good health personally, or whether they thought it was possible to be healthy despite having a chronic illness. Ironically, this omission resulted from the fact that I made assumptions that the participants would share my view of health and chronic illness, a mistaken assumption made by many health professionals and illuminated in this study when health providers seemed to fail to provide specific health information out of an apparent belief that “everyone” shared this knowledge.

Similarly, it would have been interesting to have asked participants if they felt that they were part of the health care system or the education system. Again, the fact that I did not ask these questions probably stems from my assumption that “everyone” who comes into contact with these systems, as a patient or a learner, feels part of them. These oversights might have affected the findings as participants may not have told me about certain experiences because the participants did not think they were connected to their chronic illness or limited literacy. Hopefully, this limitation was minimized due to the extensive interview questions which covered a variety of aspects of living with limited literacy and a chronic illness.

Limitations related to the researcher are shared with all qualitative studies. This is because in qualitative research, the researcher is an instrument of the research. This was

the case in this study as well. Although I reflected upon and recorded my assumptions before beginning the project, my views and thoughts will have influenced the research process. For example, while I am a health care professional, I had to remember that, during my interactions with the participants, my role was one of researcher, not clinician. At times this was very challenging. I found it very difficult not to comment when the participants told me about their unpleasant patient education experiences. Some of these experiences unfortunately reinforced my assumption that there still exist a power imbalance between patients and some health care providers.

As well, upon hearing that I was a health care professional, many participants wanted me to help them review and interpret their medical test results, find them doctors, help them fill out forms, and requested general health advice or advice on how to navigate the health system. I had to tell them that I could not provide this information during the interview phase of my study. After all of the second interviews were completed and the member checks completed, I did provide some general information about finding specialists or how the health system worked to individual participants.

One assumption that turned out to not be true was that the participants would have had routine interactions with their specialist and would be seen by other health care providers, such as a social worker, dietician and so forth, to help them manage their chronic illnesses. Instead, the main providers of patient education for the participants were their family doctor and their pharmacist. I found that this was surprising because I had assumed that the participants would receive a lot of their patient education by the specialists that treated them for their chronic illnesses.

Despite these limitations, this study does reveal the experience of individuals with chronic illness who are or have been adult learners in literacy programs in an urban Canadian setting. As with all qualitative research, the reader must decide whether the participants and their context are sufficiently similar that the findings may be transferred to other specific populations.

Areas for Further Study

This study indicates the need for and direction of future research. Further investigations are recommended related to practice, policy, and theory in the field of literacy and health. This section will briefly highlight the further research questions indicated by the results of the current study. These can be grouped according to the broad categories of literacy and health awareness among health care professionals, patient-provider interaction, health care utilization, and effectiveness of health care curriculum in literacy programs.

There is a great need for a research study or environmental scan on the current state of awareness of issues related to literacy and health among Canadian health care providers. Although there appears to have been an increase in conferences, journal editorials, and policy papers on the topic of literacy and health in recent years, we do not know of the extent to which health care professionals have integrated this information. A baseline measure of awareness of literacy limitations among patients, and knowledge of the impact of these on health education, would allow later comparison to evaluate the effectiveness of any strategies implemented to improve such awareness and knowledge. Such a baseline study could be designed using a survey methodology to find out the present level of awareness and knowledge among different groups of health care

professionals. A national email online survey could be administrated to health care professionals using the databases of either the specific national professional associations or the regulatory licensing colleges for the health care professionals. This survey could included questions about present knowledge of the issue, as well as suggested educational strategies to improve this knowledge and awareness.

Further research recommendations arise from my finding that those who accompanied participants to health care appointments and provided support when the participants were afraid to go alone, due to their limited literacy, often did not have strong literacy skills themselves. Do health care professionals assume that these supporting individuals have good reading skills? Do they tend to gear their presentations to the supportive person, even when the patient may be able to understand an appropriately worded explanation? To examine these questions, a qualitative research design could be used. The providers could be interviewed as a baseline of what are their normal communication styles with someone who brings a support person with them. Then the providers could be observed in their interactions with trained standardized patients who were playing the role of patient and support person. These provider-patient-support person interactions could be videotaped. The provider could then review the tape and note any differences between what they believed they did in such interactions and what they actually did during the taped session. Communication intervention training then could be given, and a repeated interaction videotaped and evaluated.

A further important area of study indicated by the results of the current study pertains to the relationships between health, literacy, patient education, and health resources. For example, as individuals' literacy abilities and ability to manage their own

health increase, does their health care utilization decrease? Do people who attend literacy programs begin to use fewer health resources as they learn more about health through formal instruction and informal discussions with classmates and instructors? What is the cost benefit of such literacy programs in terms of health care utilization? Is improved literacy associated with enhanced health-related quality of life? To investigate these issues, a cohort of adult learners attending a literacy program could be followed over time. Baseline data, such as self-reported health care utilization, quality of life (using an instrument such as the SF-36 (The SF Community, 2005), and literacy skill level could be recorded. Over a year, for example, data from health services utilization databases such as those mandated by the Canadian Institute of Health Information for all hospitals in Canada, self-report health utilization and physician visits, could be collected for participants to establish a baseline. Then the participants could be followed for another year while in a literacy program and the same health cost could be tracked. At the end of the time frame, health care cost pre and post literacy instruction could be calculated including the cost of literacy programs.

Another area of further research that is needed is to investigate the role of literacy programs in the transformational learning process for learners. As noted in this study, the participants went through a shifting of their meaning perspectives about their chronic illnesses as a result of being involved in the literacy classroom. The use of transformation learning theory as a lens to examine the learning process for literacy learners, could lead to further understanding of what the specific aspects or conditions that allow for the shift in meaning perspectives are. If these conditions are known, this might enable learners to

shift their meaning perspectives of other aspects of their lives through their involvement in literacy activities.

The last area of further research indicated by these study findings relates to the potential for literacy classes as powerful contexts for health education. There has been some work in the United States and Canada describing literacy and health projects in which health issues are specifically addressed within the literacy program. Some of these programs use collaborative learning in groups such as “Student Health Teams.” The teams identify health concerns, research these concerns with the help of community health practitioners and teachers, and then present the information to other students using creative media such as drama, art and music (Hohn, 1998).

Systematic evaluation of these programs is recommended to determine their effectiveness and determine best practices. A qualitative and quantitative mixed methodology could be used to answer research questions such as, “Does having students teaching other students about preventive health issues in literacy programs improve learners’ quality of life?” Or is there a reduction in health care utilization for learners? The qualitative component could be used to investigate the learners’ and instructors’ views on such things as health, health information needs, and navigating the health care system. Learners could be randomly assigned into one of two classes. Both classes would have the same literacy curriculum, but one class would study health issues. Measures such as literacy level, health care utilization, and quality of life could be collected at baseline and following the health program completion. Research work in the area of literacy and health could help to link the research and practice worlds in literacy. Darville (2003) has suggested that these worlds are not mutually exclusive but are often seen that

way. To frame research that could help and support both literacy practitioner and academic research, Darville provides a suggestion of using issues of plain language to come to new understanding of reading processes. This would be a topic area that could also link the literacy and health practice worlds as well.

Other topics areas or abilities that could be studied that link literacy and health practice are critical thinking and self-advocacy. Both these skills could be incorporated into literacy curricula. Improvements in both critical thinking and self-advocacy abilities for learners will be helpful in their overall life, and especially in health care interactions. For example, having better critical thinking abilities would help learners with chronic illnesses critically appraise the different patient education materials they receive and make informed decisions on how to manage their health.

Similarly, increased self-advocacy abilities would be helpful for learners who have to take on more and more responsibility for managing their chronic illnesses. As mentioned, the participants in this study felt more self-confidence in health care interactions as a result of being involved in their literacy classroom. This improved self-confidence could be a factor in self-advocacy. Research could be undertaken to uncover how literacy programs could facilitate improvement in learners' self-advocacy abilities. For example, the interaction of learners with chronic illnesses that are learning the skills needed to improve their self-advocacy ability in health care interactions could be investigated.

In addition to the important research questions outlined above, it is important to note that although there are a number of definitions of health literacy, at present there is not a conceptual framework for examining issues related to literacy and health. The

visual representation developed from this project could provide insights into the variables that are components of literacy and health. As well, the representation could be used to further investigate the interrelationship of these variables. In practice settings, it could be used as a basis for literacy and patient education programs and the development of curriculum material designed to reduce some of the systemic barriers to health education for individuals with limited literacy.

Concluding Thoughts

This phenomenological study shone a light on the patient education experiences for adults living with limited literacy and chronic illnesses and exposed the meaning of these experiences as one of a shifting in meaning perspective for the participants. This shifting in meaning perspective was a result of their community of practices within their literacy classrooms which allowed them to enhance their literacy abilities. This, in turn, allowed them to confront the barriers within the health care systems that block their full engagement with this health care system. Although some of the barriers continued to exist for the participants, they were better able to identify and confront them.

I began this journey to try to gain some glimpse into what it might be like to live with limited literacy and chronic illnesses and have patient education experiences. I found that it was at times very challenging and often times the health care professionals—people like myself—make this even more difficult for the participants. I believe that this is due to a general lack of awareness of limited literacy in health care. Due to the fact that I am a health care provider, I think I can have some influence in increasing the awareness of this issue. I can do this through my role as educator, both through my work in physiotherapy and also my inter-professional educational work as

well. I also have realized from this study that it appears that some health care professionals need to know how to provide patient education in a way that is understandable, for example, they need to use plain language, not medical jargon. As well, they need to work with patients to integrate patient education suggestions into the patients' complex lives.

On a larger scale, I also realized through this study that there is a definite need to look at literacy as a determinant of health, which is challenging because at present the health care system is set up as an illness system. The majority of funding of the system, I would argue, is focused on acute care, short term, and quick fixes. A determinant of health approach would entail a long term approach, with long term investments in areas such as literacy. This would require a commitment from both the federal and provincial governments, but the benefits, I think, would outweigh the cost. This type of investment could certainly lead not only to an increase in productivity and in turn the economy of Canada. But more importantly lead to an improvement in the health of Canadians. This is important for as Warda noted:

everyone of us is going to get sick one day. That's one thing that we can't hide ourselves from. But they should give more effort and clear attention to the patient because that is when a person is sick you know they always have hope the doctor, the nurse, you know, somebody can help to do something for them.

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Appendix B

Invitation to Participate

Hello my name is Judy King, thank you for allowing me to take some of your time today. I am a student at the University of Ottawa and a physiotherapist. Research is part of my work as a student. During my work as a health professional, I meet people who have different levels of reading and writing ability. Health professionals give a lot of information to patients. You could say they teach their patients. I started to wonder about how people with different levels of reading and writing skills found this teaching.

The purpose of my research is to learn more about how adults who have a health problem, and who are in an upgrading program, feel about this teaching. The research is a chance for you to talk about how your level of reading and writing may have affected your understanding of information from health professionals and how this affected your ability to manage your health problem.

I would like to talk to students who have a health problem. The health problem might be asthma, diabetes, high blood pressure, arthritis, or any other physical problem that they have had for at least 6 months. Health information is any information or advice that a health professional has given you to help you understand and manage your health problem. It might be handouts, pamphlets, diagrams, exercises, videos, or going to a patient education class.

If you agree to be in the study, I will interview you for about 45-60 minutes. The interview will happen at a good time and place for you. This can be at your school or at your home. I may also ask you for a second interview to answer some other questions. The second interview will be shorter.

If you join the study, I will make sure that I do not mention your name. A made-up name will be used anytime I talk or write about what you told me. The only people who will look at the information from the interviews will be myself and my supervisor at the University of Ottawa.

You will receive \$50 for the interview.

If you would like to be part of this research or ask any other questions about the research, please telephone me. If you decide to be part of this research, I will ask you to sign a form that explains the research and your rights.

Thank you for your time

Judy King

You may also contact my supervisor Dr. Maurice Taylor at 562-5800 extension 4037.

There are two copies of the consent form, one you may keep.

I, _____, am interested in being part of this research.
My signature shows that I understand the research the way it is described.

Participant's Signature

Date

Researcher's Signature

Date

Would you like to receive information about the research when it is done?

☐ **Yes**

☐ **No**

Your mailing address

Appendix D

Demographic Form

Age:	Gender Female: Male:
Languages	
First Language:	Other Languages:
Language used in health care interactions:	
Language of health care professionals:	

Chronic Illness:
Number of years living with the chronic illness:
Diagnosed date (if known):
How often do you have to go to the doctors or hospital because of your illness?
On average how many times per month?
Medications- number: type:
Daily: Weekly: prn:

Other Treatment requirements- Oxygen, dialysis etc.
--

Living arrangements
Alone: Significant Other: Number of people in the household:
Apartment: House: Other:

Schooling
Years of completed school:
Upgrading Program: How many years:

Occupation:
Retired- When: On Disability- When:

Appendix E

*Field Note***1st Interview****2nd interview**

Where	Notes/Comments/ Thoughts	Where	Notes/Comments
When		When	
Consents signed			
Interview		Interview	
Profile		Fill in missed information for Profile	
Number of Tapes		Number of Tapes	
Transcribed		Transcribed	
Narrative		Narrative	
Member Check		Member Check	
Thank you-\$		Thank you-\$	
Changes Made after Member Check		Changes Made after Member Check	

Appendix F

First Interview Guiding Questions

Introductory Statement

Many people get advice about how to live with their illness from a health care professional. I am going to ask you some questions about the health care advice and information that you have received about managing your health problem.

Guiding Interview Questions

I understand that you have _____(chronic illness), do you have any other long term health problems?

What kind of health information, patient education, or advice do you need to help you deal with your illness and take good care of yourself?

1. Medical information about the illness.
2. Information about daily living, for example, diet, exercise, activity level (etc.).
3. Teaching about how to take medication, about tests (e.g., blood, x-ray, radiotherapy etc.).
4. Information about how the illness has changed your family life.
5. Information about health places in the community.
6. Information about how to get around the hospital.
7. Help to fill out forms.
8. Information about how you feel, how you cope, how the illness has changed your life.

Can you tell me a bit about what happens when you go to a medical/health appointment? Can you walk me through the process please?

1. Do you go alone or with someone to your medical appointments? Do you take the same person? Why do you take some one with you?
2. What language do you use when speaking with health care professionals?
3. Do you tell them that you have difficulty reading? Or do you tell them you have a learning disability?
4. Do you tell the health care professional that you attend a literacy program/upgrading program?
5. How do they react to this information?

Written Patient Education

Can you show me any pamphlets or papers that you have gotten from your doctor or nurse or other people about your illness? (*or if participant does not have any pamphlets show a few examples of pamphlets)

Do you receive pamphlets from health care professionals? From whom?

Is the information useful to you? Can you use it at home? Do you put it up somewhere so you can see it to remind you?

What do you like/not like about it?

What is easiest to understand?

How can we make it easier for you to use?

What kind of information is most helpful (print, audio, video, personal contact)?

Verbal Patient Education

What about when your doctor, the nurse, or another health care professional talks to you?
What do you like/not like when they talk to you?

How could it be better?

Do you use this advice/information? Why or Why not? Do you feel you have to use the advice?

Do you get enough information to help you deal with your condition (How/when to take medication, how to prevent future problems etc.)?

Do you find it easy to use/understand what they tell you?

How could they do it better? What advice would you give them?

How would it be most helpful for your health care provider to share information with you?

What do you not find helpful?

If you do not understand some information do you ask questions?

Are there puzzles/things that you do not know about your illness?

If you have questions about your illness, who do you talk to? A health care professional (doctor, nurse, pharmacist, etc.)?

Do you talk to friends or family about your health problem?

Do you try to find health information yourself?

Where do you get health information (e.g. television, Internet)?

Who helps you? Who helps you the most?

How would you like to get health information (in a group, verbal, written, video etc.)?

Learning Components

Now I have a few questions about how you like to learn about your health:

Do you like to be alone with a teacher?

Do you like to read information?

Do you like to watch a video?

Do you like to have someone explain it you verbally? Demonstration?

Do you use a computer? Do you like to use a computer? Does it help you learn?

If you have a skill to learn (mention a skill needed), do you prefer to practice alone or in front of a health care provider?

Learning Setting

What kind of place makes it easier for you to learn?

To learn about your health, where would you rather be in a

Hospital, Clinic, Health care professional's office

Community Centre

Home

Upgrading/Literacy Classroom

Gym

Support Group

Elsewhere (specify where)

Group Learning

What makes you comfortable when you are learning in a group?

Have you ever attended an information session with other people who have the same health condition as you? Support groups?

Have you been asked to attend but did not attend?

Have you used any of them?

What did you think of them?

What did you like/dislike about them?

How could they be better?

General Questions

What makes a good teacher? Do you think of health care professionals as teachers?
Could they learn to be better teachers?

Can you describe a good and bad experience you have had receiving health information?

Do you think that receiving health information or advice would be different for someone who doesn't read and understand as well as you do?

Can you give me some examples of ways that the situation would be different?

What would make the situation easier or better?

Can you think of ways that information or advice could be easier for people with limited literacy to get and to use?

How do you think you could have more control over your health? What information do you need to have more control over your health?

Final question

Do you have anything else to tell me about how health care professionals could do a better job in giving health information and education to people with long term illnesses and conditions like yourself?

Appendix G

*Second Interview Guiding Questions***Learning Process- How**

Did you know anything about _____ before you were told you had it?

How do you think about _____ (your illnesses) now that you have some information about it from your doctor? Has the information or advice changed the way you think about your illness?

How do you think about your illness or conditions? Do you think that it is something that just happens or that it was your fault? Does that change whether or not you take the advice?

Some people, when a health care professional asks them “do you understand,” say they understand even if they don't. What would be a better question for the health care professional to ask the patient?

When you are going to the doctor's do you plan on what you are going to ask or say to the doctor before going in? Do you write it down? Do you change what you are going to ask once the doctor has started to talk?

Do you want to know about your illness and how you can control it? Or do you not want to know about your illness?

Is it okay to ask your doctor questions?

How much time should a doctor spend with you?

Learner- Who- Literacy/ Language Issues

How much do you understand when you go to the doctor's? Do you understand all of what he or she says or just some of it, and has that amount changed since starting school?

How do you think learning how to read, write, listen, and talk better has affected your health and controlling your illnesses?

Which one of reading, writing, listening, or talking skills do you think you use the most when going to see the doctor? Which do you use the least? Have these improved with going to school?

Do you think if you could read, write, listen and speak better your experience in receiving health information would be different, that is, would you ask more questions?

What do you think that health care professionals say to other people with your illness? Do you think that they change what they say to you because they know you have some difficulty with reading and writing?

Do you tell health care professionals that you have literacy issues? Do people ask you if you can read? What would you say if they did ask you? Do you think your doctor treats you differently because you have some difficulty with reading, writing, listening, and speaking?

How would it make a difference if you spoke the same language as your health care professional? Can you read and write in your own language?

Who is responsible for your health and for getting information about how to deal with your health problems?

Learning Context- Where- Setting

How do you feel when you leave the doctor's office? Confused, frustrated, and/or guilty that you haven't followed his/her advice (etc.)?

Where do you feel that you learn/understand the best? Is it in the doctor's office, at home when you think about what he or she tells you, or after you talk to someone else?

Where do you learn better, in your doctor's office or at the hospital?

Do you talk to the pharmacist or not talk to him/her because it is out in the open and others can hear you?

When do you think you learn better about your health after you have had a health crisis? For example, if you had to go into the hospital or you got sick, right after you have been told you had something or later?

Learning Content - What- Patient education, health information and advice

Why do you think that people only talk to their doctor about their health problems? Why don't they talk to the nurses or other health care professionals?

What do you think the term health information means? What do you think the term patient education means? What do you think the term health advice means? Are they all the same thing or different things?

What is the role of the health care professional, is it to help you understand your illnesses, to get you to change the way you think about your illnesses, to make you change your behaviour?

Is it easier to follow advice about taking medication than to follow advice about changing your diet or exercising more? Why?

When do you tell your doctor that you are not following his/her advice?

Is everybody's _____ the same, or is it an individual experience?

Do you provide health information to someone else in your family or friends that have a health problem? Do you go to health appointments with them?