

Adults Living with Limited Literacy and Chronic Illness:

Patient Education Experiences

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ABSTRACT

The purpose of this study was to investigate how Canadian adults living with limited literacy and chronic illness made meaning of their patient education experiences. The study used a hermeneutic phenomenological research design and employed three data sources over a nine-month period. Data was interpreted and analyzed as it was collected, following common procedures for phenomenological studies. Five themes emerged from the data: roles and relationships, language and health care interactions, living between worlds, mismatched expectations, and powerlessness. Findings suggest that the participants shifted their understanding of their patient education experiences because their literacy abilities improved through work in their literacy classrooms. Implications of the study are discussed for adult literacy practitioners and policy makers.

INTRODUCTION

A recent report from the Canadian Council on Learning (2008) describes the links between adult literacy skill levels and health. This report suggests that 60% of adults in Canada do not have the skills needed to adequately manage their health and health care needs (Canadian Council on Learning, 2008, p.20). In many cases, limited literacy skills affect a person's ability to use health services effectively, take medications, and understand other information related to health. This is

especially true for adults with chronic illness and limited literacy. Most of the health information they get comes through patient education.

However, research on the link between literacy and health has tended to focus on policy issues, program evaluation, and assessment tools. Patient education studies have centered on improving the readability of materials and increasing the awareness of literacy issues among health care professionals (Canadian Council on Learning, 2007; Canadian Council on Learning, 2008; King, 2007; Osborne, 2001; Perdue & Degazon, 2001; Rudd, Moeykens, & Colton, 2000).

The main guiding questions for this investigation were: what is the meaning of patient education experiences for adults with limited literacy and chronic illness? And how do these patient experiences affected these adults and what types of barriers are encountered in patient education settings for these adults.

LITERATURE REVIEW

Canada and the United States share common concerns about the incidence of low health literacy. Yet each country has tackled the problem and solutions from a national perspective, rooted in its own health care system. A converging point between the countries lies in a small body of literature that has looked at literacy and health from the perspective of people living with limited literacy.

In a seminal study, Parikh and colleagues (1996) examined the relationship between shame and low functional literacy in two health care settings—the emergency room and a walk-in clinic in a large urban hospital. By interviewing patients and using the Test of Functional Health Literacy in Adults (TOFHLA) Parker, Baker, Williams, , & Nurss, (1995) , the authors found that 43% of participants had low health literacy. Of this group, 67% admitted to problems with reading and had not shared this knowledge with a spouse because they were ashamed. In a

Canadian context, this same shame emerged in a qualitative study that examined adults' responses to being screened for reading ability using the Rapid Estimate of Adult Literacy in Medicine (REALM) Davis, Crouch, Long, Jackson, Bates, George, et al (1991). Brez and Taylor (1997) found that the risk of exposure and the stigma of illiteracy were prevalent among participants who had been recruited through a local community literacy program and had recent experience as hospital patients. The participants did not want people to find out about their literacy difficulties and "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).

Furthermore, other provincial and regional evidence has emerged around adults with limited literacy and their interactions with the health care system. In a large urban university health care facility, the Centre for Literacy of Quebec (2001) reported that health care professionals decided how much information to give hard-to-reach patients based on cues such as a reluctance to read or other life factors. Although the adult patients in the study were not assessed for literacy abilities, the health care providers described hard-to-reach patients as "disadvantaged or poor patients, older patients, patients who smoke and have bad health habits, and patients who live in poor neighborhoods" (Centre for Literacy of Quebec, 2001, p. 74).

Without first discussing the patients' information needs, some of these health care professionals made incorrect assumptions about how much or what type of information to give individual patients. In addition, most of these patients claimed that written documents were not directly helpful because (a) they did not like to read, (b) the documents were only in French or in English, or (c) their caregivers took responsibility for reading. In a follow-up to this study, Santo, Laizner and Shohet (2004) examined the literature on alternative methods of health

communication. They found that most evaluative studies on the effectiveness of plain language and audiotapes excluded adults who did not speak English and were unable to read or had other physical or cognitive deficits.

Gillis and Quigley (2004a) used an ethnographic research design to explore the links between literacy and health in a rural setting in Atlantic Canada. They interviewed 46 adults whose lives had been affected by limited literacy. Twenty-five of the participants were enrolled in adult learning programs; 21 others were recruited through a hospital-based diabetes outpatient clinic and community-based health agencies. Interviewees ranged in age from 18 to 55 and had completed school grade levels from grade 1 to grade 12. The researchers used a reflective adult learning process during data collection. They asked participants to talk about past experiences in literacy and health, to reflect upon the meanings of those experiences, and then to suggest what action they thought was needed on a personal, community, or policy level to make the situation better. Key themes that emerged from the data included (a) social isolation due to physical distance from larger communities; (b) lack of public transportation in rural communities; (c) limited opportunities for and/or decreased access to employment, recreation, health care, education, and support services; and (d) limited accessibility of affordable health care resources. Participants' suggestions were brought to provincial policy makers: (a) reduce barriers to enrolling and attending literacy programs in rural areas, (b) support client advocates to help people move through the health care system, and (c) use mobile health units to take health information and services to people in rural areas.

Although these studies have attempted to shed light on literacy and health, much more work needs to be done in this area. As the literature shows, there is a paucity of information illuminating the lived experiences of adults living with limited literacy and chronic illnesses.

METHODOLOGY

Because the issue of literacy and health is so complex and multi-layered, I used a qualitative research design for this study. I tried to uncover the actual experience of patient education for individual adults by employing an inductive, interpretive hermeneutic phenomenological method (van Manen, 1997). This approach provided for dynamic interplay among six research activities including (a) our interest in the phenomenon, (b) investigation of the participants' lived experiences, (c) reflection on the themes that characterized the phenomenon, (d) description of the phenomenon in written form, (e) maintenance of a pedagogical relation to the phenomenon, and (f) balancing of the research context by considering both parts and the overall context (van Manen, 1997, pp. 30-31). The setting for the study was a provincial community-based literacy and basic skills (LBS) program offered in two school boards in a city in Eastern Ontario, Canada.

The curriculum of the LBS program was designed to provide adults with literacy, numeracy, and employment skills in a multilevel classroom environment. All instructors had Ontario teaching qualifications; some had additional certification in adult literacy and basic skills, special education, reading, or English as second language. Learners who enrolled in the program wanted to complete high school, upgrade their basic skills, or prepare for employment.

Study Participants

I recruited participants through their literacy classrooms. I selected 14 adults from the LBS program using the following criteria: (a) availability, (b) age (over 18), (c) willingness to describe the patient education experience in English, and (d) a chronic illness diagnosis. I defined chronic illness as a health problem such as asthma, diabetes, high blood pressure, arthritis, or any other physical problem that had lasted for at least six months.

Data Collection

I collected three kinds of data over a nine-month period: two sets of semistructured interviews, field notes, and a researcher's journal. I undertook a pilot study to test the demographic form, interview guide, and interview approach. As a result of the pilot study, I made substantial changes to the data collection tools, especially in the types of questions used in the interview schedule. Categories of questions in the final schedule included patient education formats (written and verbal) and components of patient education experiences such as the setting and group learning. These categories of questions were drawn from the literature review.

Initial interviews lasted for about 45–60 minutes. In them, I built relationships with the participants and focused on descriptions of patient educational experiences. Approximately, 3 months later, I interviewed all 14 participants again for about 30 minutes as a way of delving further into the themes that emerged from the preliminary data. I conducted both first and second interviews either at the literacy program site or in the participants' homes.

I maintained notes throughout the study consisting of raw data based on observations and conversations in the field. In addition, I kept a research journal during all phases of the study to record my perceptions, observations, insights, feelings, and the rationales for decisions around coding and analysis. Later, I transformed these various data sources into research narratives.

Data Analysis

Data analysis occurred concurrently with data collection and interpretation. I used the procedural steps outlined by Colaizzi (1978, pp. 59–62) to analyze the data in this phenomenological study. First I read each participant's description of the phenomenon in order to acquire a feel for it. Then I returned to each participant's original transcript to extract significant statements and draw out the meaning for each significant statement. These steps were repeated as I aggregated the

data into clusters, allowing for the emergence of themes. I then integrated the results into an exhaustive description of the phenomenon based on statements of identification. Trustworthiness was established through member checks, (which included participants reviewing the summary narratives of the interviews) thick and rich description, an audit trail, and triangulation. The final write-up of the study included a text description of what participants experienced and a structural description of how the phenomenon was experienced (Creswell, 2007).

RESULTS

We divided our findings into five main themes that emerged from the analysis. Following the tradition of hermeneutical phenomenology, we described the phenomenon of patient education through the eyes of participants. The five themes include: roles and relationships, language and health care interactions, living between worlds, mismatched expectations, and powerlessness. Each study participant is identified by a pseudonym.

Roles and Relationships: The Family

Study participants interacted with a number of different people—doctors, nurses, pharmacists, and others—during their patient education experiences. But of particular interest to this study was the role of family members. Study participants thought of family members as interpreters, readers, and mediators when they faced barriers to communication with members of the healthcare team. Participants asked their children to explain terms or words that a doctor had used or that they had written down if a child had not been with them. When they were given patient education pamphlets, they took them home so their children could help them with the reading.

Woven into this theme was another important health-related connection between participants and their families. Participant health could also affect the health of family members.

For example, Sonia and her son both had asthma. Sonia had some difficulty managing her own asthma due to her limited literacy and felt that this made it difficult to manage her son's asthma as well.

Language and Health Care Interactions

Although patient education can be delivered in many ways, the two main formats encountered in this study were printed material and verbal interactions. These formats were often used in conjunction with each other. In provider-patient verbal 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 also received written patient education materials in many different forms. These included pamphlets from a doctor or pharmacist that listed specific drug information as well as materials promoting health for the general population. Participants did not find this printed information helpful, and therefore they did not usually keep it as reference material. One of the main reasons for this was that the printed materials used vocabulary that the research subjects did not understand. As she was describing a situation when she had to sign a consent form for tests, Lynn observed, "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."

Living Between Worlds

The participants clearly felt that they lived between two worlds. One was the world of health, and this encompassed living with a chronic illness. All of the study participants perceived themselves as different from others in society who were well and lived healthy lives. The other is the world of literacy. Because they had gone back to school to improve their literacy abilities, participants believed that they were different from the majority of society whom they perceived as having no difficulties with literacy. They tried to situate themselves in society by engaging as

much as they could, but were 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. Sophia did not want anyone to know that she had asthma and did not want anyone outside of the class to know that she had limited literacy because “It is not public, it is personal, it’s personal.” 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. In a similar vein, 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 had been able to help her understand her health and deal with the health care system.

Living with a chronic illness means having to deal with not knowing from one week to the next how you will feel. This was the case for participants who were unable to go to their literacy classes due to worsening symptoms of their conditions. 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.

Mismatched Expectations

Participants reported entering into patient education experiences where health care providers often did not meet their expectations. Getting health information and being treated with respect were the main issues. Study participants expressed frustration at not being given patient education or not receiving specific enough information. They were disappointed when their need for specific knowledge about their particular health conditions was not satisfied. Sonia, for instance, felt that a health care provider should teach people how to breathe when they are having asthma difficulties. “I educated myself on how to breathe; some people don’t know about

this, you know. It wasn't introduced to them.”

In addition to expecting health information, the participants in the current study expected to be treated with respect by health care providers. Participants believed that respect was a key to establishing trust, and that trust allowed 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. Monique also commented about not being believed. This made her feel that she was not being respected. She stated that these experiences usually occurred when people did not listen. Because she had lived with asthma all her life, she had had many episodes of difficult breathing that 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 labor with her son. She stated that finally people believed her and that was why she was diagnosed correctly.

Powerlessness

The findings that emerged from this study also indicated that the participants felt powerless. Their feelings of powerlessness, including the feeling of fear of exposure, were rooted in the experience of living with limited literacy. Within the health care context, most of the participants felt obligated to follow advice without question. Another feature of the theme was that none of the participants had told a family doctor that they had difficulty 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's 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.” In one case, a participant believed that she had

altered this feeling of powerlessness. Since returning to the LBS program, Louise stated, “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.”

DISCUSSION

In this section of the paper, we present our interpretations formed from the findings. These interpretations are drawn from health literacy literature as well as from adult learning theories relevant to patient education experiences. This is intended to further deepen understanding of the phenomenon under investigation: patient education experiences of adults with limited literacy and chronic illness.

Roles and Relationships: The Family

The different roles that families take on were also noted in the Baker et al. study (1996). In it, participants spoke of bringing family members to appointments to help them navigate the health care system. The authors noted that some participants would not go to an appointment with a doctor unless someone who could read went with them. Requiring a third party to help them cope with the health care system may present a problem for individuals with limited literacy. The presence of family members may limit their ability to present their concerns to health providers. As suggested by the Canadian Council on Learning (2008), people's ability to understand and use health information is vital to managing both their own and their family's health-care needs.

Language and Health Care Interactions

Language issues have been raised in the majority of research studies in literacy and health (Brez & Taylor, 1997; Centre for Literacy of Quebec, 2001; Gillis & Quigley, 2004b; King, 2007; Rudd et al., 2000). Language used in health care interactions, especially medical jargon, can be a

challenge for most of us. However, it is a much greater challenge for people with limited literacy because, for them, it is not just the vocabulary that is difficult but all aspects of health care interactions. For example, Baker et al. (1996) investigated the health care experiences of people with low health literacy in the United States. They noted that language issues contributed to barriers that made health care system navigation difficult—issues such as deciphering complex forms and understanding provider-patient interactions in which complicated medical language was used.

Living Between Worlds

Participants' feelings of social isolation and living between worlds are not surprising when you understand that individuals with limited literacy are generally marginalized by the larger North American society. Freire (1970) noted that often within a 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” (Freire, 1970, p. 74), and they are expected to integrate into that larger society. Freire proposed that these marginalized people are part of society already, and live inside the structure that made them. They are only marginalized in relation to the norms of the society that they live in and whose routine workings produce them.

Mismatched Expectations

The participants' frustration at not being given patient education or not receiving specific enough information has also been found in other studies. For instance, Reid and colleagues (1995) found a mismatch between what health care professionals thought was important for a patient to know and what the patient wanted to know when reading an information pamphlet about diabetes. Participants in the present study were frustrated when their need for specific information about

their particular health conditions was not satisfied. In addition to expecting appropriate health information, the participants in our study expected to be respected by health care professionals. Participants in the Centre of Literacy of Quebec's (2001) study expressed the "need to be listened to and respected" as well (Centre of Literacy of Quebec, 2001, p. 18).

Powerlessness

The theme of powerlessness is consistent with other studies. Individuals with limited literacy have reported living with shame (Breen, 1992) and fear of being exposed in social settings including a health care context (Parikh, Parker, Nurss, Baker, & Williams, 1996). As well, adults with limited literacy have mentioned that they have felt fearful, anxious, angry, stupid, embarrassed, and ashamed and are suspicious of others within health care settings (American Medical Association, 1999). Baker et al. (1996) reported that few participants had told their health care providers about their reading difficulties because they felt embarrassed about not understanding.

PATIENT EDUCATION EXPERIENCES THROUGH THE LENSES OF ADULT

LEARNING THEORIES

Through the full range of patient education experiences (as described in the main themes and categories), the participants took new information and integrated it into the context of their previous experiences. This resulted in new knowledge that helped them deal with their health conditions. How this occurs for someone living with limited literacy can be understood in part through three adult learning theories: transformational learning, situated cognition, and critical theory.

Individual Learner: Shifting Perspectives

Transformational learning theory provides a basis for understanding how adults interpret and

make sense of their experiences and act in their worlds (Mezirow, 2000). The theory also attempts to explain how adults use critical reflection in learning. At an individual level, it appears that the participants' patient education experiences resulted in a shifting of meaning perspectives related to their chronic illnesses. Diagnosis appeared to be the disorienting dilemma that began the process. The majority of the participants had had previous knowledge or understanding of their chronic illnesses, but these meaning schemes and perspectives needed to be altered before the participants could adopt behaviors recommended for the management of these diseases. Participants' meaning schemes were deconstructed and reconstructed as a result of the patient education experiences and their improved literacy abilities. This process of perspective transformation also included behavioral change, the ultimate goal of patient education: the teaching of self-management strategies for living with a chronic illness.

Learning Context: Creating New Knowledge

A cornerstone of situated cognition is cognitive apprenticeship where individuals learn as a result of modeling, mentoring, coaching, scaffolding, and experiential learning (Wenger, 1998). We can use this viewpoint to explain how the participants learned new knowledge, skills, and behavior both from their peers in the class and from their literacy instructors. 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 a common understanding. The primary and most significant community of practice for our study participants consisted of the instructor and classmates in the 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. We were surprised to note that none of the participants had belonged to a community of other people with the same chronic illness (such as a support group for people living with arthritis) or indeed any health related group. The literacy classroom was a community in which participants learned not only literacy skills but also social skills that helped them deal with chronic illness and interact with the health care system. This occurred both through formal discussions about health issues and through informal discussions.

System: Coping with the Power Imbalances

Participants were linguistically limited in their ability to conceptualize health and illness because of their lack of medical vocabulary. Such limitations hinder a patient's ability 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. But it limits people's ability to control their own health without the help of those same powerful health care professionals. In the present study, participants were very much aware of their responsibility for their own health, but their feelings of powerlessness were often barriers to taking a more active role. As noted earlier, the literacy classrooms were the participants' health learning communities, and these communities were comprised of the participants' instructors and peers. None of them had formal health care training. The health care system presented many barriers to the participants, and they did not view it as a learning community. The system incorporated and maintained a power imbalance between patients and providers. All participants recognized this imbalance of power, and it affected their dealings with the health care system.

The participants' patient education experiences often left them feeling powerless and marginalized. They felt voiceless in the system. This is indeed a feeling that many of us share

with study participants. Welton (2005) believes that many in society 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” (Welton, 2005, p. 180). For the participants, however, the sense of powerlessness actually changed as their meaning perspectives shifted through their interactions with communities of literacy practice. Being a member of this adult literacy class provided the support, confidence, and confidentiality that participants needed to cope with their illnesses outside of their immediate families. As a result of this unintended learning, they acquired a certain self-knowledge and a personal sense of power.

DISCUSSION

The essence of the participants’ patient education experiences is best described as the interplay among the five themes: roles and relationships, language in health care interactions, living between worlds, mismatched expectations, and powerlessness. It appears that the participants shifted toward perspective transformation—from powerlessness, dependence, isolation, not having expectations met, and not understanding the language, to having some power, some independence, some fellowship, some ability to have expectations met, and some ability to learn and understand the language of health care.

In addition, it seems that patient education, in the form of a provision of a diagnosis, set in place the process of perspective transformation. Through the community of practice found within the LBS classroom, participants were able to overcome or at least lessen some of the barriers and take control of their lives. This enabled them to manage their chronic illnesses better. For example, the participants’ ability to read improved through literacy classroom instruction. With better reading skills, they were better able to find health information on their

own. Participants encountered barriers such as difficulty obtaining or understanding patient education information intended to help them manage their chronic illnesses. But as the participants' literacy abilities and self-efficacy improved through their community of practice, these barriers were reduced. Note that none of the barriers disappeared completely for the participants because they were part of, or reinforced by, the health care system.

As a way of presenting this study's results, we developed an organizing framework that highlights the three components that form the essence of patient education experience for adults with limited literacy and chronic illness. Figure 1 represents the individual learner, the learning context, and the system. <PLEASE INSERT FIGURE ABOUT HERE> The five themes that emerged from the data are found in the individual learner component. The next component of the framework is the learning context. This is the community of practice, the learners and instructors in the literacy classes. Enhancing their literacy abilities by participating in this community of practice began the process of shifting meaning perspectives for the participants. The arrows joining the learning context with the system are the different avenues for patient education. The dotted line represents barriers within the system that the participants had to break through to access patient education experiences. The system component is divided into the primary sources of patient education: family doctors, pharmacists, friends and family, and the participants themselves.

Central to the framework is a shift of meaning perspectives as interpreted through the lens of transformational learning. These perspectives were based on the participants' values, beliefs, expectations, and feelings about chronic illness, and were formed before they entered the literacy class. Through the lens of situated cognition, we can see that participants' meaning perspectives were altered as a result of participating in a community of practice—the literacy

class. While the educational experience began when participants heard their diagnoses, the learning process that occurred in class was a catalyst for individual participants to become more fully engaged in patient education experiences. Enhanced engagement allowed them to learn to manage their chronic illnesses. Through a lens of critical theory, we can see that although the participants continued to face the previously encountered systemic barriers to patient education access, they changed how they saw and interacted with these barriers because of their shifts in perspective about chronic illness and limited literacy. The literacy class experience and participation within that community of practice enabled participants to start to overcome these barriers.

IMPLICATIONS

Literacy Practitioners Partnering with Health Care Professionals

One of the key findings of the 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 easy for them to understand and deal with the health care system and obtain appropriate care.

The literacy class was the community of practice. It was an important place, a safe place to learn about health and the skills needed to navigate the health care system. Literacy practitioners, though, may face challenges in obtaining appropriate health education resources for their students. Literacy instructors need to work with health care providers and learners to find resources that learners consider helpful and needed. Participants suggested that health care

providers such as nurses could come into their classes and discuss general health issues. This has been done successfully in Massachusetts where literacy programs create student lead health teams for collaborative learning. 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).

Results of this present study also highlight the need to increase health care providers' awareness of the impact of limited literacy on patient education experiences. An important policy paper from the Institute of Medicine (2004) pointed out that health care providers bring their own expectations to health care interactions. The authors of that paper 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" (Institute of Medicine of the National Academies, 2004, p. 2). Such increased awareness might occur if literacy and health care practitioners could work together to help learners manage their own health and deal effectively with the health care system.

Successful collaborations between health care professionals and adult literacy practitioners have already resulted in research projects and workshops that link health care professionals and literacy practitioners (Centre for Literacy of Quebec, 2001; Gillis, Quigley, & MacIsaac, 2005). One such collaboration is the Canadian Public Health Association's National Literacy and Health Program. It provides resources to promote awareness among health professionals of the links between literacy and health (Canadian Public Health Association, 2008).

Policy

Results from this study also suggest that there is an urgent need for literacy and health policy development. It is difficult to determine where issues related to literacy and health should fall

within the political and bureaucratic systems. In other words, should such policy changes be health driven or literacy driven? What levels of government should be responsible for spearheading literacy and health initiatives? Similar questions have also arisen in research conducted by Gillis and Quigley (2004a). They brought together literacy, health care, education, and social service organizations. As a starting point, the researchers found that building relationships among organizations required an investment of time. 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 addition, the results of this study seem to suggest that literacy and health is an issue of public accountability at the systems level, at the organization and program level, at the patient-provider level, and at the instructor-learner level. Such thinking is consistent with the definition of health literacy from the Institute of Medicine (Institute of Medicine of the National Academies, 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. (Institute of Medicine, 2004, p. 5) This do this within a community and a system.

Our study clearly points to the involvement of each of these levels while acknowledging the challenges faced by individual patients, health care providers, and the health care system itself. Working in tandem, we could achieve a collective vision, one in which

All people in Canada have the capacity, opportunities, and support they need to obtain and use health information effectively; to act as informed partners in the care of themselves, their families, and communities; and to manage interactions in a variety of settings that affect health and well-being. (Rootman & Gordon-El-Bihbety,

2008, p. 1)

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Figure 1. The Essence of Patient Education Experience

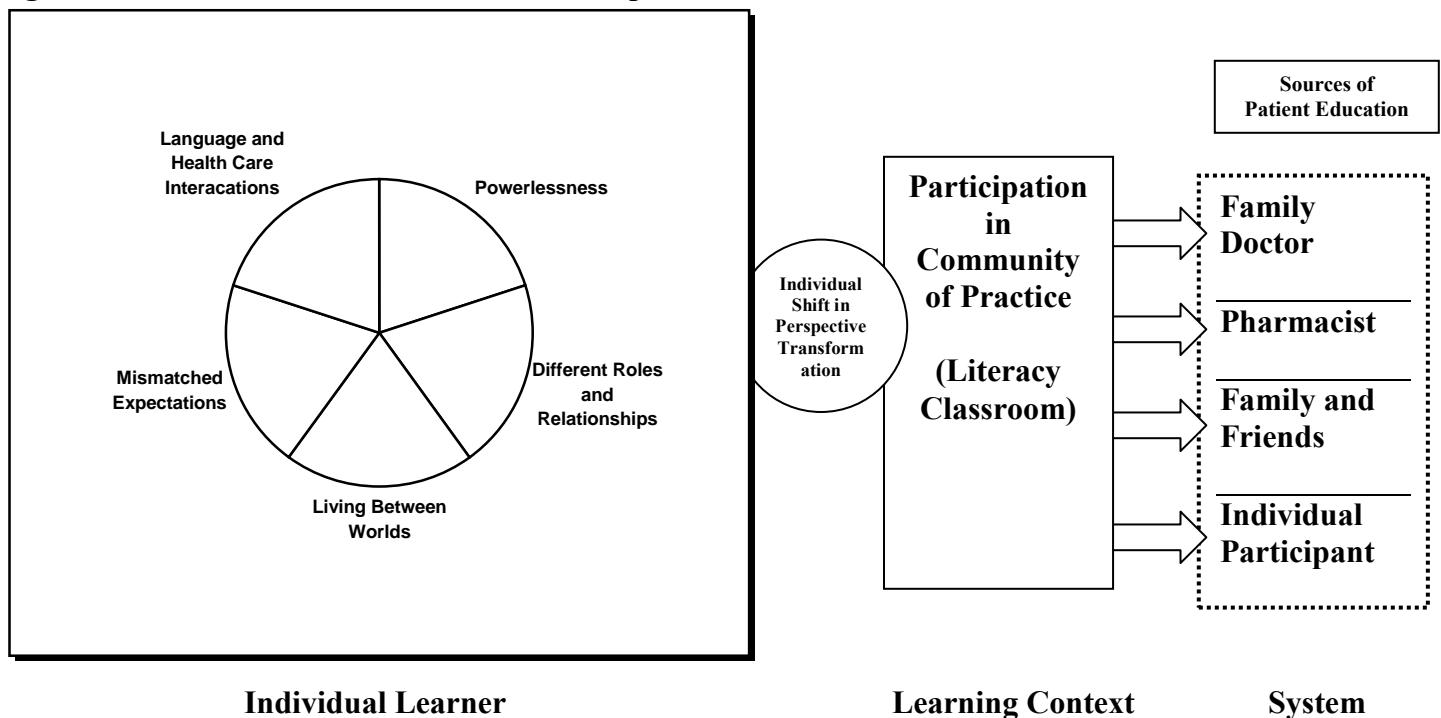


Figure 1. The essence of patient education experience. The individual learner component holds the five themes that emerged from the data. The learning context is the community of practice, the literacy classes. The arrows represent different avenues for patient education. The dotted line represents barriers to accessing the system. The system component is divided into the primary sources of patient education. Central to the framework is a shift of meaning perspectives as interpreted through the lens of transformational learning.