

# Literacy, Learning and Health – A social practices view of health literacy

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## Abstract

In this paper, I use a social practices view of literacy to challenge dominant conceptions of health literacy. Health literacy is frequently defined as an abstract skill that can be measured through individual performance tests. The concept of health literacy as a skill neglects the contextual nature of reading and writing in health care settings. It risks ignoring the many ways in which patients access and comprehend health information, make sense of their experience and the resources they draw on. The paper presents findings from a study of forty five literacy and ESOL (English for Speakers of Other Languages) students' health-related reading and writing practices in the north-west of England. I suggest that health literacy needs to be understood as a situated social practice and that it is a shared resource frequently achieved collectively by groups of people, for example families. I conclude with some reflections on the implications of my research for adult education practice.

## Introduction

As part of the 'New Literacy Studies' (NLS), the role of literacy in institutional contexts and social settings that require ordinary people to interact with officials and holders of professional knowledge has been widely studied (see for example Barton and Hamilton 1998, Jones 2000, Fawns and Ivanic 2001, Papen 2007). The primary aim of these studies is to investigate how people engage with the formal and bureaucratic texts that are part and parcel of institutional procedures, not to assess how well they score in literacy tests. Nevertheless, many researchers adhering to a social practice view of literacy are interested in the implications of their studies for teaching and learning in formal and non-formal settings, including schools and community colleges. Researchers have challenged dominant literacy policies (Crowther, Hamilton and Tett 2001, Papen 2005, Luke 2005, Jackson 2005, Barton et al 2007). Based on their insights into learners' lives, they have suggested ways of linking adult basic education more closely to learners' existing literacy practices and to those topics that are most relevant to their own experiences (Hamilton 1999, Barton et al 2007). Health is one such topic. Many adult learners suffer from health problems and they regularly interact with health care providers (Papen and Walters 2008, see also Barton this volume). The

present paper investigates the role of reading and writing in relation to people's health and to the health care they receive. Based on interviews with forty five adults, I discuss the significance of various literacy practices in relation to how people manage ill health, communicate with health care providers and interact with the institutional world of medical care. In the conclusions, I draw out the implications of my research for our understanding of patients' health literacy and how it can best be supported.

### **Health literacy: The dominant view**

Links between ill health and low levels of education are widely acknowledged (Stationary Office 1998, Pamuk et al 1998, Health Canada, Statistics Canada and Canadian Institute for Health Information 1999, Harris, Sainsbury and Nutbeam 1999). In recent years, health educators, medical researchers and adult educators have increased their efforts to explore this relationship in more detail and to understand the links between patients' levels of literacy and their ability to assess and benefit from health services. Researchers and politicians, from the fields of adult education and health, have become increasingly interested in patients' 'health literacy' and how it can best be enhanced. Health literacy can be understood as 'the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions' (Seldon et al 2000). North American research is at the forefront of work on health literacy and British studies frequently draw on their American colleagues' expertise (see for example von Wagner et al 2007, Ibrahim et al 2008). Overall, the interest in health literacy is practice-oriented, aiming to develop new ways of helping patients to improve their health literacy (see for example the 'Skilled for Health Demonstration Programme', <http://www.dfes.gov.uk/readwriteplus>). Most studies adopt a concept of health literacy similar to the one expressed in the above definition. The dominant view is that health literacy is an ability possessed by individuals (Weiss et al 1995, Baker et al 1999, Nielsen-Bohlman, Panzer and Kindig 2004, Lurie and Parker 2007). It consists of a set of competencies transferable to different contexts. Because health literacy is treated as being context-independent, it is assumed to be measurable through abstract tests. Accordingly, there is much research into patients' levels of health literacy, this being seen as a prerequisite for developing new tools to teach health literacy.

Health literacy tests are individual performance tests. They measure patients' ability to understand specific texts (such as patient information leaflets) and their familiarity with medical terminology. The two most used tests are REALM (Rapid Estimate of Adult Literacy in Medicine) (Murphy et al 1993) and TOFHLA (Test of Functional Health Literacy in Adults) (Baker et al 1999). Both tests were developed by researchers in the US. They are regarded as useful instruments to assess patients' ability to cope with medical

terminology and to understand instructions from health providers. Both tests have been used by researchers and health educators in Britain (see for example Beaver and Luker 1997, Gordon et al 2002, Ibrahim et al 2008). In recent years, TOFHLA has been adapted for specific audiences, including Spanish-speaking patients and those visiting dental surgeries (Guerra and Shea 2007, Lee et al 2006, Gong et al 2007). A new shortened version of TOFHLA, based on one text – the nutrition label of an ice cream container – also exists (Weiss et al 2005).

But what do these tests really measure? Few researchers appear to have asked this question. Clinicians and health educators accept them, either because they believe in them or because they are the only scores available. Are there no alternatives to 'testing' people's health literacy?

## Methods

The study, *Literacy, Learning and Health (LLH)*, started from the assumption that there are other ways of exploring people's ways of reading and writing in relation to their health than to ask patients to take a health literacy test. It is one of the few studies that applies a social practice view of reading and writing to the area of health literacy (another example is Freebody and Freiberg 1999). The overall aim of this study that spanned a period of two years and eight months was to examine how literacy, learning and health are related to each other. Crucially, the research set out to understand this link from the perspective of patients, i.e. users of the health care system, not providers. In line with the ethnographic tradition and similar to other studies in this volume, the aim was to capture 'ordinary' people's point of view. The study, which was funded by the then Department of Education and Skills, included forty five adults. At the time of interviewing them, all but two were students in literacy and ESOL (English for Speakers of Other Languages) classes. Informants were recruited from such classes in various places across the north-west of England including Preston, Halifax, Lancaster and Bolton. Our aim was to identify and describe what written texts they come across in health care settings, how they engage with these, what difficulties they experience and what other sources of information they draw on<sup>1</sup>. We also asked students and teachers about their experiences with health as a topic in their classes (Papen and Walters 2008).

The study was grounded in a view of health literacy as social practice. Accordingly, we talked about health literacy 'practices' rather than health literacy 'skills'. Setting aside the notion of skills, we were able to explore what people do with reading and writing rather than to 'assess' how good (or bad) they are at what they are doing. This is not to say, however, that we were not interested in people's abilities. But we did not define these as narrow skills. Rather we conceptualised them as context-bound and changing

competencies, some of which, as I will show below, were not located in individuals but in groups and social networks.

Informed consent was obtained from all participants. Our regular visits to the literacy and ESOL classes allowed the study participants to get to know us and to talk to us informally about our research. This was an important step in obtaining informed consent. The consent form itself and the signature we asked for, in some cases provoked discomfort; in particular some participants who were applying for asylum were wary of the official nature of this text and the requirement for a signature. We gave full anonymity to all participants and we removed all personal identifiers so that the respondents are not identifiable and cannot be identified through the details of the story. The Preston, Chorley & South Ribble Research Ethics Committee approved the study protocol.

Interviews were semi-structured and open-ended. Unless the respondent objected (two cases), the interviews were taped and fully transcribed. Twenty-nine informants were non-native speakers of English. The majority of them were interviewed using interpreters. We also collected many types of texts (including web sites printed out for patients, patient education leaflets, handwritten notes, diagrams drawn by a doctor, forms, etc.) and we discussed these texts with our informants.

In our interviews, we started simply by asking people to recollect recent experiences of being ill and seeing a doctor. We then raised more specific questions about written texts they may have come across on these occasions. Our aim was to gather detailed accounts of people's dealings with health care providers and of their experiences with texts such as forms, package inserts and websites. Difficulties figured frequently in our informants' accounts. Yet, we also learned of the many resources people had. Pamela who had had several miscarriages learned to search the internet for insights into what had happened to her. When Peter, who had several chronic diseases, found that his doctors frequently asked him to list all the (up to) eighteen different pills he was taking, he typed up a list of all his medication. Pamela's and Peter's actions are central to the conception of health literacy that we developed through our research: a view of health literacy not only as deficit, but also as a resource. This echoes the view taken by Hamilton in her study of older people's literacy practices (see this volume).

Six out of the forty five study participants became key informants. They were interviewed several times. We visited them in their homes or accompanied them on a visit to their doctor. The data set is complemented by field notes from these visits. The six key informants were chosen because they had interesting experiences of dealing with health providers and written texts to share and they were happy to share these with us. Ideally, we would have liked to include a greater number of key informants, but within the time available this was not possible. Interview transcripts and field notes were

analysed using a process of coding, supported by the software Atlas-Ti. Codes (themes) were identified on the basis of the research questions and through a process of careful reading of all data. In the following sections, I summarise and comment on the main points of analysis emerging from the data.

### **Health care environments are ‘textually-mediated’ social worlds**

To begin with, the study revealed that many health care processes are ‘textually mediated’ (Smith 1999, Barton 2001) thus requiring the patient to engage with various sorts of written texts. We found that changes in people’s health status are amongst those experiences in their lives that draw them into new literacy practices (see also Hamilton this volume). According to the participants in the LLH study, a variety of text types are used in doctor-patient interactions and in the provision of health care more generally. These include patient information leaflets and consent forms, prescriptions, charts and wall posters. These texts are part of how health professionals inform patients on the diagnosis, treatment and prognosis of their disease. The following examples illustrate this further.

Anna, a Polish woman, whose smear test had shown an abnormal result, had been given a leaflet ‘What your abnormal result means’. When she had to have a loop excision treatment (to remove the affected cells), she received another leaflet explaining the procedure. Maria, another informant, had seen a nurse about what she suspected to be a cold sore. At the end of the consultation, the nurse printed out for her a leaflet on the causes and treatment of cold sores. Leaflets, such as these, are ‘interpretive resources’ (Coupland and Williams 2002:420): sources of meaning-making. However, the extent to which these resources are being taken up by patients varies and I will comment on this further below.

Patient education and information leaflets are designed to present medical information in terms accessible to the lay patient. Judging from what our informants told us this was often the case. Anna spoke very positively about the different leaflets she had received from her doctors. She also explained that the consultant had repeatedly invited her to raise any questions she had. She told me that when the doctor first explained the procedure to her, he drew an image of her uterus on a piece of paper to show her from where the affected cells would be taken.

Patient education leaflets often use a writing style mimicking oral conversations between a doctor and a patient. They address the reader in the second person and use a question/answer format to convey important information about a disease or a treatment. The question-answer format was commented upon positively by Shanaz, another informant, who told us that when she looked for health information on the internet she was attracted by sites using this structure.

But patients do not only need to read and absorb written information. They also need to speak and listen, and dealing with written texts is often part of a speech event. As Anna's example has shown, text – in this case visual text – is embedded in talk. Text is also embedded in action and health texts derive their meaning in part from the functions they take within health care practices. This indicates the need for a contextualised approach to understanding health literacy. The following sections amplify this.

### **Health literacy is embedded in social relationships**

As a social context, health care is shaped by relations of authority. Doctors and other health care providers are granted positions of power and they hold authoritative knowledge. Patients are commonly expected to listen to the experts' verdict on their condition and to comply with any advice given. Literacy is part of the process of establishing and actualising these relations of power. The following example illustrates that health texts are frequently implicated in 'relations of ruling' (Smith 1999).

When Debbie, a twenty eight year old mother of two boys, had had a scan, the conversation with the consultant – rather than focusing solely on the ovarian cysts he had detected – unexpectedly turned to contraception. Debbie did not understand why the doctor talked to her about contraception and why he gave her a leaflet about the coil. At the time, she had no need for contraception. When the consultant told her that she '*could end up pregnant*' and that '*they couldn't offer her sterilisation*', she '*felt like a 10 year old that their mum and dad were saying be careful*'.

Debbie took the leaflet. But she was not interested in its content. The leaflet became only useful to her much later, at the time of the research interview, when her personal situation had changed and she decided to have a coil fitted. When the doctor gave her the leaflet about the coil, he ignored Debbie's own views on her situation.

Debbie's case reveals the importance of understanding health literacy within the social relations structuring health care provision. Debbie's rejection of the advice given by her consultant and her lack of interest in the leaflet may be falsely interpreted to result from her failing to understand what the consultant explained and what the coil was about. But Debbie's non-compliance had nothing to do with a lack of skills. It signaled her opposition to the identity (as a young woman needing contraception) the consultant tried to impose on her.

## Health literacy is part of institutional processes and practices

The above examples have already shown that health texts are part and parcel of how health care is dispensed. Appointment letters, letters containing test results and new patient registration forms are an integral part of the institutional processes of health care provision. In one of the study locations, we discovered that general practitioners frequently print out leaflets for patients at the end of the consultation. Marie's doctor did this and she was not the only informant who mentioned this practice. It is reasonable to assume that Debbie's consultant's insistence on discussing contraception was part of the health services' general policy of providing information about contraception to women of child-bearing age. As the example shows, this was done although the information was not solicited. My next example further illustrates the importance of examining particular health texts in the context of the institutional practices and policies they are part of and which give meaning to them.

Forms stand for the institutions that issue them. Forms, by the way they are written and through their functions in specific contexts, can deny people access to resources. They may require the applicant to take on an identity they are opposed to. After several years of living with lupus, a severe and chronic auto-immune disease, Kate was unable to work and so ill that she applied for a disability allowance. When Kate and her husband sat together to fill out the application form they struggled with the amount and detail of information about her disease they had to supply. They did not know much about lupus. In Kate's words, the form was '*hopeless*' and '*an absolute nightmare*'. It contained many '*gobbledygook*' questions, which she simply did not understand. Kate resented that she had to provide a lot of information that was already contained in her patient file. Being in a lot of pain day in day out, she could not understand that there was a need for her to 'prove' how ill she was. Kate could not understand why her consultant's verdict on her condition, contained in her patient file, could not simply be passed on to the Department of Social Services. But the state's discourse of welfare obliged Kate to take on the position of applicant having to make a case.

Kate's experience with the application form for a disability allowance also shows that bureaucratic texts can be written in a register applicants are not familiar with. Kate told us that she had difficulties finding the appropriate words and that she did not know how to spell them. But this was only part of the problems she had with the form. The broader issue was her objection to the procedures she was subjected to, i.e. having to make a case for something that was blindingly obvious to her and not being able to rely on her doctor's words when doing so.

## **The emotional side of health literacy**

Health literacy is not only about dealing with information on a cognitive level. There is an emotional side to health literacy. Several of our respondents spoke about the fear they felt when learning about a serious disease. This could stop them from engaging with health information.

When Katherine's husband, who had just been diagnosed with advanced cancer, was given a leaflet to explain the chemotherapy he was to receive, he put the leaflet in a drawer and ignored it for a week. As Katherine explained to us, they wanted information '*in their own time*' and they felt that the consultants had a tendency to confront them with too much information in a way they found impossible to bear.

Not everybody I spoke to read the leaflets or brochures they had been given. Some people did not want to know. When Kate was first diagnosed with lupus, her GP gave her several leaflets. At first she read them. But she soon stopped because she was terrified by their content. She did not want to see herself in the descriptions she found. Katherine also told us that it could be dangerous to know too much about an illness. Dipta found that after she had detected a lump in her breast that her doctor considered to be harmless (and which later disappeared), she did not want to search for more information on the issue. She simply wanted to forget about this experience that had frightened her.

## **Challenging the deficit view of health literacy: People's strategies for overcoming difficulties they experience**

The people in the LLH project dealt with the literacy practices of health care with varying degrees of confidence and competence and some of the study findings could be seen to support the deficit view of health literacy prevalent in current health policy. ESOL students for example mentioned difficulties explaining their symptoms and understanding the doctors' words. The native speakers talked about struggles with specific genres (see Kate above). But it is important to see that patients, including those commonly represented as having limited basic skills, are not without resources when it comes to dealing with the literacy and language demands of health care settings. In the following, I discuss the strategies the study participants employed to deal with health literacy demands.

Non-native speakers dealt with difficulties by preparing themselves for a visit to a doctor. Before going to the surgery, Elisabeth, a French speaker, wrote down some of the points she wanted to tell her doctor about. Sonia (from Poland) and Jing (from Macau) both used dictionaries to write down words to use when explaining their symptoms. Sonia prepared a list of words and phrases in advance of her appointments to use as prompts when talking to her GP. Jing used her dictionary to write down words for her doctor to

read. Dictionaries also helped her and others when they tried to understand leaflets they had been given.

Pamela (a British woman) searched the internet to find out what was involved in a colonoscopy that her husband had to have. She made notes of what she read. Jon (also a native speaker) used the internet and health books to get information about his daughter's thyroid problems. He and others in the study actively sought out information to complement or clarify what their doctors had told them.

One of the most common strategies the people in the LLH project used was to draw on others who could help them with the literacy tasks involved in dealing with ill health. They drew on family members, friends and neighbors as literacy mediators. Kate offers a good example of the importance of literacy mediation in relation to health literacy. Kate relied to a large extent on her sister Jenny to help her deal with lupus. When, after five years of having lupus and getting progressively worse, Kate lost the trust in her consultant, she asked Jenny for help. On behalf of her sister, Jenny searched the internet for information about the disease, its prognosis and treatment. She wrote to two consultants and got Kate referred to one of them. She also wrote to the local MP, when Kate was refused a hip replacement. Mediation, as in the above example, is 'task-specific' (Cuban, this volume). However, it also stretches further to include general emotional support. Kate relied heavily on her sister and the rest of her family for the kind of emotional help she needed in order to cope with her illness. When Dipta, a young woman from India who had come to Lancaster a year before I met her in the study, had to see a doctor for the first time, she asked her mother-in-law to accompany her, even if her English was no better than Dipta's. These examples show that literacy mediation in health care contexts involves what Cuban (this volume) calls 'caring literacies'.

Literacy mediation was mentioned by nearly all participants in the LLH project. Its key role in health care suggests that health literacy is often 'distributed'. By this I mean that it is not simply a property or an attribute of an individual, but that it is shared knowledge and expertise. It resides in the patient's social network. An individual's health literacy could thus be seen as the sum of what she knows and is able to do herself and what she is able to achieve with the support from friends, family and other significant people in her environment. At a more general level, this view of health literacy as being collectively achieved also challenges individualised notions of responsibility and risk, which underline current health policies (Green, Lo Bianco and Wyn 2007).

## **Conclusions: What does the *Literacy, Learning and Health* project tell us about what health literacy is?**

What can we learn from the above examples about the nature of health literacy? And what conclusions can we draw regarding the role of health as a topic in adult education?

First of all, the study shows that health literacy is always ‘situated’ (Barton, Hamilton and Ivanic 2000). Rather than conceptualising it as an abstract attribute or a generic ability of the mind, it is more helpful to think of health literacy as how people use reading and writing in specific health care contexts. Crucially, the situated approach that I argue for in this paper also requires researchers to look at the other partner in healthy literacy: the doctors and nurses and how they communicate with patients (Rudd 2008).

The examples presented above demonstrate that specific health literacy practices, such as reading a leaflet, need to be examined not in isolation, but as part of a health care episode – the time period over which patients are dealing with a particular symptom or disease. Adopting this perspective allowed me to take account of my informants’ earlier experiences with health professionals, their prior knowledge and understanding of their disease and any experiences they might have accumulated during the current period of illness. In Anna’s case, I was able to do this through my repeated conversations with her. When Anna read the leaflet she had received from her doctor after she returned home from her consultation, she looked at its content in the light of what the doctor had told her during their meeting (cf. Pollock et al 2008). How she made sense of the information it contained also related to other texts she consulted, for example, Polish and English websites on the topic. This was not the first time Anna had had such a result and how she reacted to the leaflet was also a matter of her prior experience with abnormal smear tests.

A further important finding from the LLH project is that health literacy includes dealing with hierarchical social relationships, which can disempower the patient who is at the receiving end of health information and health care practice (Murtagh and Hepworth 2003). Informants were aware of how little time doctors had for them and some struggled to raise the questions they wanted answers for. Information given, including leaflets, is restricted in what it includes (often the dominant medical view on a specific disease and its treatment) and how it addresses the patient (as a passive recipient of knowledge) (Dixon-Woods 2001). Current health policies in Great Britain are supportive of patients’ greater involvement in their care (Department of Health 2001, 2004). Policies are driven by the model of the ‘informed patient’ who is actively involved in their health care and any decisions related to it (Henwood et al 2003). Whether patients take up these opportunities may in part be a matter of their ‘skills’. But the situation is much more

complex. My conversations with patients revealed that they may not necessarily conform to the informed patient ideal, but may remain 'passive'. Lupton (1997) suggests that this is also a form of agency showing that people's reactions to illness are shaped by a variety of needs and emotions. This echoes my earlier argument about the affective side of health literacy. Another reason for apparent passivity I found is that patients may see no need for information other than what their doctor tells them. They may want the doctor to be in charge and take responsibility for decisions (Pollock et al 2008). Yet other patients go off to gather knowledge but may find that this is not accepted by their doctors (Dray and Papen 2004). These scenarios reveal that it is important for researchers, educators and health care providers to shift their attention away from the patients' assumed skills deficits to their meaning-making abilities and practices. This includes acknowledging that patients learn about health and disease in their own diverse and complex ways, following their own logic (Armstrong and Murphy 2008) and drawing on sources physicians might not see as legitimate (Green, Lo Bianco and Wyn 2007). This is important because we can only identify gaps in patients' knowledge and experience (and ways to reduce these) once we know what they actually do and are able to achieve.

### **Implications for policy and practice**

The implications of the LLH study for literacy and health policies in Britain are manifold. First and foremost, as explained already, the study challenges narrow ideas of health literacy as a measurable and abstract concept. The study findings cast doubt on the validity of any pronouncements of patients' health literacy based on tests. Tests such as REALM neglect the contextual nature of reading and writing in health care contexts and the power issues involved in modern health care practice. They risk ignoring the competencies and experiences patients can draw on. They do not take account of the collaborative nature of many literacy activities. New ways of 'assessing' patients' health literacy allowing for a more complete picture of what patients can and cannot do are required.

With regard to the role of health in relation to learning and teaching, NLS have repeatedly argued that literacy, numeracy and ESOL provision needs to be built on a thorough understanding of learners' existing literacy practices and their social contexts (see Hamilton 1999, Papen 2005, Barton et al 2007). Health, as the LLH project has shown, is part of learners' everyday concerns and thus could be seen to be an ideal candidate for a social practices based curriculum. However, we have found in our study that in many literacy, numeracy and ESOL classes health is not a frequent topic (Papen and Walters 2005, Papen and Walters 2008). Many ESOL beginners' classes devote some time to helping learners understand the British health care system and teaching them the vocabulary needed to converse with a

doctor. But very few of our forty five informants expressed an interest in making health a more central topic of their class. The views of those who participated in the study indicate that health is not an easy topic to address in large, mixed (gender, age, ethnicity) classes, and that even those who frequently deal with ill health do not necessarily feel that their class is the right place to talk about disease. Therefore, any attempt to give health a greater prominence in literacy, numeracy and ESOL classes needs to be thought through carefully.

The above leads me to suggest that literacy, numeracy and ESOL classes may be better placed to support health literacy by offering units on more general and transferable abilities, such as searching skills (for those using the internet) and critical reading and critical language awareness (useful when reading patient information leaflets). Much could also be done to ensure that literacy education takes sufficient account of the multimodal nature of contemporary texts, supporting students in their critical readings of visual language. Visual images are prominent in health texts and they are a powerful means to convey meanings. Health care is just one of many institutional settings people are affected by and in all such contexts, communication is often shaped by hierarchical social relations, creating a need for the 'users' to assert themselves in the face of bureaucracies and top-down policies. Assertiveness training (i.e. how to talk confidently to a person of authority, see also Cuban this volume) thus has the potential to benefit learners in many areas of their lives. Such training would also need to discuss how written texts are used as part of talk, as seen in some of the examples discussed in this paper. The widespread use of social networks suggests that literacy, numeracy and ESOL classes could also explore the role of literacy mediators in learners' lives, the aim being to support and develop this already well functioning strategy.

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