

Literature review



Understanding literacy and health

A literature review from four fields of research:

- medical research and health education
- literacy studies
- linguistics and discourse analysis
- medical anthropology and sociology

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Published by the National Research and Development Centre for Adult Literacy and Numeracy

This document is also available in pdf format from ${\bf www.nrdc.org.uk}$

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Design: www.chapmandesign.net

Cover photography: INSADCO Photography/Alamy

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1. Introduction

This paper provides an overview of and commentary on existing research in the area of literacy and health. The aim of the paper is to discuss the contributions of four fields of research to our understanding of health literacy. These four fields are: medical research and health education; literacy studies; linguistics and discourse analysis; and medical sociology and anthropology. Researchers from each of these four fields have studied the role of reading and writing in health-care contexts, albeit from different perspectives and with different conclusions. Over the course of the following pages, what these perspectives are, and in what ways they contribute to our understanding of what health literacy is and how it is learned and taught, will be explained. Several other disciplines also contribute to ongoing research and theorising in this area, for example communication studies and psychology. These have not been included here.

The literature search that forms the basis for this paper was carried out as part of a research project into the relationship between literacy, learning and health (see Papen 2004; Papen and Walters 2005, 2008)¹. This project studied lay people's (i.e. patients') reading and writing in relation to their health and how they deal with the literacy requirements of the UK's health-care system. It involved 44 students in literacy or ESOL classes who were interviewed about their experiences as patients².

In the following summary of our findings, no attempt is made to offer a complete overview of research in the area of health and literacy. Only research on patients' (that is lay people's) health literacy has been included, not studies reporting on what doctors, nurses and other health-care providers can contribute to improving patients' health literacy. On the other hand, many titles that do not explicitly talk about literacy, but which are relevant because of how they discuss issues related to the role of written texts in the interaction between doctors and patients, are covered. This is for example the case of some research in Discourse Analysis, which has been included in the present paper, along with an explanation of why they are of interest for health literacy research. The choice of research titles and the commentary on these is also influenced by my (the author's) own background as a literacy researcher (whose disciplinary origin is in social anthropology). I look at literacy from a particular perspective – the view of literacy as social practice. More will be said about the concept of literacy as social practice and how it relates to health literacy in Section 4 of this review.

2. Definitions and concepts

In academic research, disciplinary background often correlates with specific theories and ideas on the topic studied. This is the case when looking at research in the broad field of health and literacy. There are striking differences in the way in which what is commonly called 'health literacy' is defined and discussed by medical researchers, health education specialists, sociologists, anthropologists, linguists and literacy researchers. The following sections are organised to cover the four broad areas of research in the area of health literacy that are covered in this review: medical research and health education, literacy studies, linguistics and discourse analysis, and medical anthropology and sociology.

Because each of the four fields mentioned above has its own way of approaching the topic of health literacy, in each section the way the studies that have been included define health literacy is commented upon. Broadly speaking, health literacy can be understood as 'the ability to read, understand, and act on health care information' (World Education: http://www.worlded.org/us/health/lincs). This is a very general definition that many people can accept. However, as will be shown, there are differences in the way researchers explain what exactly this 'ability' to make use of health-care information means and what factors are involved in deciding whether a patient is able to read and understand health-care information. There are also major differences in the research methods used to study health literacy and these will be commented on.

3. Medical research and health education

From the literature that we looked at, it seems that medical researchers and public health specialists frequently conceptualise literacy as a cognitive ability or a skill that can be measured and controlled (see for example Weiss et al. 1995, Baker et al. 1999). Such a view of literacy is usually called a 'skills view' of literacy (Papen 2005, Barton 2007). The idea of literacy as a skill is close to what others mean when they talk about 'functional literacy' (Verhoeven 1994). The term functional literacy is also used by many medical researchers interested in patients' literacy (see for example ten Have et al. 1991). To be functionally literate means to be able to perform activities and roles involving the use of written texts in a socially acceptable and desired way. It also means that people are able to cope with the often complex information and communication practices characteristic of our modern society. For patients, this means that they can understand a piece of health information to the extent that it allows them to use this information for its intended purpose and for their own benefit. But health literacy is not only about understanding information: it is also about being able to communicate health information (Gazmararian and Parker 2004). This is important both for health professionals and their patients. Without the latter being able to tell them what they are experiencing, it is very difficult for a physician to make a diagnosis. In our own study, we found this aspect of health literacy to be very important, in particular for those of our participants whose first language was not English.

We can see from the above, that medical researchers define health literacy to include reading, writing and oral communication skills in relation to health. In addition, the term health literacy is often understood to also include knowledge about health and disease, about treatments and ways of keeping oneself healthy (see for example McMurray et al. 2007, Morrow et al. 2007). Thus, the concept of health literacy can be quite broad and this is similar to how we talk about literacy in relation to other areas. For example, when we refer to computer literacy, we also often mean more than being able to know what functions the icons on a computer screen stand for. People with high computer literacy are expected to also understand how a computer, including software and hardware, works. We can see from the above that what researchers do or don't mean when they talk about health literacy is not easy to specify and it often is a matter of debate.

Medical scientists often think of different degrees or levels of health literacy that can be found among patients. Accordingly, much research in the medical field aims to develop and apply tools to measure patients' health literacy levels (see for example Davis et al. 1991; Parker et al. 1995; Moon et al. 1998; Parikh et al. 1996; Bennett et al. 1998, Baker et al. 1999, 2004; Gordon et al. 2002; Wallace et al. 2006, 2007). Based on such assessments, researchers and medical education specialists attempt to predict the likelihood of patients benefiting from written health information and from health services more generally (Weiss et al. 1995). Such research has found, for example, that people with low levels of literacy are less likely to be aware and make use of screening and prevention facilities (Lindau et al. 2002). They have also been found to be less likely to adhere to prescribed courses of treatment (Kalichman et al. 1999) or to know much about

their chronic disease (Williams et al. 1998). These findings are important because they show that, as in many other areas where complex knowledge is required, people only participate to a limited extent and they only make partial use of services and opportunities.

Over the past 10 years, attempts to clarify the relationship between patients' health literacy (as measured by a health literacy test), their health-related behaviour (e.g. adherence to treatment) and their health outcomes (their general health as well as the success of specific treatments) have continued to be at the forefront of medical research into health literacy. This is indicated by the large number of studies published in 2006 and 2007 (see for example Mancuso and Rincon 2006, Gazmararian et al. 2006, Paasche-Orlow et al. 2006, Yin et al. 2007). Health literacy tests have also been used with specific populations, for example elderly persons (Sudore et al. 2006, Wolf et al. 2006, Baker et al. 2007) or Spanish-speaking immigrants to the US (using a Spanish version of a test first designed in English, see Lee et al. 2006, Bennett et al. 2007, Guerra and Shea 2007). There are now also tests to measure 'functional oral health literacy' (Gong et al. 2007, see also Richman et al. 2007). US-based researchers have been at the forefront of medical research into health literacy and the most commonly used tests to measure patients' health literacy levels were all developed in the US. However, these tools are also being used for research in Britain (see for example Beaver and Luker 1997, Gordon et al. 2002, Dani et al. 2007).

Parallel to developing health literacy tests, medical researchers have studied the readability of health documents such as consent forms (Raich et al. 2001) or patient information leaflets (see for example Basara and Juergens 1994, Newton 1995, Glazer et al. 1996, Guidry and Fagan. 1997, Molina 2001). Many of these studies match sample texts with assumed 'reading ages'. They measure literacy levels of health texts by comparing them with levels of formal literacy obtained by children in schools. One such study, carried out in the UK, looked at the readability of patient-information booklets on breast cancer. Using tools developed in the US, the study found the information booklets to have a high reading age and to be unsuitable for many women (Beaver and Luker 1997). Studies assessing the complexity of health texts are helpful when we try to predict how a particular group of patients might react to a specific text, such as a leaflet on diabetes. But these studies can only offer approximate indications of how accessible the text might be and they cannot tell us anything about how it is read in specific situations by particular patients. Another strand of research seeks to find out more directly from patients what they think about texts such as information leaflets. Such studies use surveys and interviews to ask patients specific questions about health texts and any difficulties they may have in understanding them (Weiss et al. 1995, Raymond et al. 2002). Such research can have unexpected results. A recent study of the information needs of first-time mothers over 35 years of age has found that many of these mothers, rather than feeling empowered by the large amount of information received from their midwives and nurses, were overwhelmed and worried about knowing too much (Carolan 2007).

In recent years there has been much research on information provided through the internet (see for example McLellan 1998, Kalichman et al. 2001, Berland et al. 2001, Gafni et al. 1998, Bental et al. 1999, Nicholas et al. 2001, Smart and

Burling 2001, Eysenbach and Kohler 2002). The internet is a focus of interest for medical researchers as well as those in the field of communication studies. Many of these studies are concerned with how accessible information published on the internet is and what its quality and reliability is. Other studies focus directly on the patient as the user of internet-based information and they address the role of the specific personal and cultural context within which lay people deal with any issues related to health and disease. An example is Drentea and Moren-Cross' (2005) recent study of an internet website for mothers. They privilege the users' (i.e. the mothers') perspective and examine the role of virtual communities in developing support amongst mothers outside the formal health-care system. For example, they have studied how mothers help each other by sharing information and providing explanations of messages received from doctors or found in books or on websites.

4. Literacy studies

In the previous section, research on health literacy carried out by medical researchers and health educators was summarised. Now the focus is on Literacy Studies, a field of research populated by linguists, education researchers, psychologists, social anthropologists and others. Literacy Studies is a field of research that is concerned with the role of reading and writing in different social contexts and situations, and by different groups of people. The focus of Literacy Studies goes beyond reading and writing in schools and formal education. It is interested in looking at the importance of literacy in people's everyday lives and in institutions and workplaces. This is also what makes Literacy Studies relevant for the topic of this literature review. A small number of studies have looked at the role of written texts in health-care contexts and these will be discussed later in this section. Before this, how literacy researchers define reading and writing, and the extent to which their understanding of literacy differs from the way the medical studies referred to in the previous section think about literacy, will be explained.

In the previous section, the skills view of literacy was introduced. In recent years, literacy researchers, in particular those seeing themselves as belonging to the 'New Literacy Studies' or NLS (see Gee 1996; Street 1993, 1999, 2001; Papen 2005) have suggested that literacy is 'more than skills' (Papen 2005; see also Street 1993, 2001; Barton and Hamilton 1998). They see literacy as encompassing more than a fixed and measurable set of cognitive abilities. Instead, they conceptualise literacy as social practices: as activities which are always embedded in specific situations and contexts and whose characteristics and meanings can only be understood within these contexts.

Most people find it relatively easy to accept diversity in spoken language. But there is also a lot of variation in written language. What we do with written texts and what functions they serve varies greatly. In our daily lives we make use of many forms of texts; these use many stylistic varieties of written language and they serve many purposes. A sign at the hospital is designed to help patients find the place they are looking for. An email written to a friend conveys news or primarily aims to let them know that we have not forgotten about them and are keen to stay in touch. Other texts serve other purposes. So if we look at the uses and meanings of written texts in our everyday lives, we can see many different 'literacy practices' (Street 1993, Barton and Hamilton 2000, Papen 2005). Health literacy practices are a specific set of such literacy practices: those dealing with physical and mental well being, with diseases, their symptoms and treatments.

In its most straightforward sense, the term literacy practices can be translated as denoting the 'uses and meanings of reading and writing' (Papen 2005). In order to explain precisely what this means, we need go back to what we said earlier about literacy: that it is always embedded in specific activities and contexts. The concept of literacy practices links reading and writing to such contexts. Practice refers to social activities, which we recognise as belonging to a specific domain of our lives or of society. The social practices of classroom teaching (Fairclough 2003) are a good example. Health-care practices are

another example. Completing a registration form is part of hospital admission practices and these in turn belong to the domain of health care. The practices of health-care provision in England include the ways of working of the NHS and other providers, the rules and conventions that govern the NHS and the social relationships between health-care providers and patients. As with any other social practices, health-care practices are characterised by a degree of stability and regularity – there are conventions, rules and common ways of accomplishing things. In addition, health-care practices are based on a recognised body of knowledge and expertise that informs standards of good practice. Related to this, there are expectations about people's behaviour and shared goals and who is in charge of what (e.g. doctors, because of their medical expertise, make the diagnosis). But there is also some variability – not everything always goes according to plan and people don't always behave in the way they are expected to. This is important for research on health literacy, because it means that how specific patients engage with a piece of information received from their healthcare provider, or a form they were asked to complete, does not just depend on their general educational level but is related to many other factors and can never be fully predicted and controlled. More about how the idea of literacy as social practice can inform research on health literacy follows.

Literacy as social practice: what does this mean for research on health literacy?

The idea of literacy as social practice is very relevant to research on health literacy, as already mentioned. It allows researchers (and practitioners) to move beyond the skills people theoretically have, as measured in literacy or health literacy tests. Instead, we can attend to concrete situations where people use their literacy to accomplish specific activities and fulfil particular goals. Rudd et al. (2004), for example, have accompanied patients walking through a hospital to try and understand what sense they make of the signs around them and whether they had any difficulty finding their way through the hospital. Studies such as this one can identify the factors contributing to patients understanding or not understanding health information, whether they find it relevant or ignore it, who might help them in negotiating their way around the literate environment of the hospital, etc. Rudd and her colleagues (who are researchers of public health) carried out a qualitative study, working with a small number of patients. Most research in Literacy Studies is also qualitative, involving a limited number of study participants.

There is little doubt that literacy and health are related and that people with lower levels of education are likely to have less access to health care and in general are likely to have poorer health than those who are better educated. There are many studies confirming this link (for example, for the UK see Black et al. 1980, Stationery Office 1998; for the US see Pamuk et al. 1998; for Canada see Health Canada 1999; and for Australia see Harris et al. 1999) and literacy researchers (including myself) do not deny that there is a connection between education and health. But the studies referenced here also acknowledge that socio-economic status is closely related to education. This suggests that income is an important factor in relation to health. We can see from this that the precise ways in which education (and with it literacy) and health are related aren't fully

clear. Freebody and Freiberg (1997, 1999) have pointed out that many studies on literacy and health carried out by medical researchers have been unable to specify what exactly the relationship between literacy and health looks like. In some cases, this is because these are large-scale surveys which have to generalise and cannot include details of individual cases. In other cases, they are based on health literacy tests that measure abstract skills but cannot tell us much about how specific patients in specific situations deals with particular texts. The issue is further complicated by the fact that not all medical studies which intended to confirm the assumed link between literacy and health have actually found a correlation. Guerra and Shea (2007), for example, found that in a sample population of 1301 Latino and African-American adults there was no significant relation between functional health literacy and physical and mental health status. Others have also acknowledged that the evidence linking health literacy to differences in health status or risky health behaviour is patchy (Howard et al. 2006, Wolf et al. 2006). These studies confirm Freebody and Freiberg's view.

Qualitative studies on health literacy, such as the work by Rudd and her colleagues, can help us specify the kind of relationships between health and literacy that large-scale surveys (such as the ones mentioned in the previous section) have identified. Small-scale qualitative research has the advantage that it can study people in more detail and over longer periods of time and, because researchers try to establish close relationships with their informants, there is greater chance of people offering their detailed views on an issue as private and sensitive as their own health. This has the potential to make it easier for the researcher to understand the complexity of individual circumstances and the reasoning behind their decisions and actions. In the Literacy, Learning and Health project, we found that for many of the students it was difficult for them to talk about their health issues in detail, and only those people who we had time to get to know well were ready to share their experiences with us.

Literacy researchers working on health tend to use qualitative methods, focusing their attention on specific patients or groups of patients, aiming to find out how they engage with the literacy practices of specific health episodes. Dray and Papen (2004) have discussed the case of one of the authors engaging with a leaflet given to her by her physician. They have also looked at what other information she drew on, independent of what she was given by her GP. Fawns and Ivanic (2001) describe the experiences of six university students using a particular form to apply for support from the NHS with their health-care costs. They found that the students had difficulties with particular parts of the form, for example specific terms. The form asked them intrusive questions about their personal financial situation, and while they generally accepted that this had to be so, the students struggled with the limited space they had to explain the details of their case. The form is powerful because it serves as a gatekeeper regulating access to resources. Freebody and Freiberg (1997, 1999) have explored the role of written texts in communications between doctors and patients. They have, for example, described a consultation involving a GP and his elderly patient who suffers from headaches. In response to her request for more and stronger medication, her GP refers her to medical research that believes most headaches to be caused by stress and therefore to be unlikely to respond to medication. These remarks show the doctor relying on knowledge which is part of the

authoritative body of medical expertise contained in medical journals or research reports (Freebody and Freiberg 1999). This example shows the importance of social relationships in health-care settings. The doctor's authority is secured because it is codified in written form. By contract, Freebody and Freiberg (1997) show that patients' own information sources (e.g. neighbour's advice, something heard on the radio or seen on TV) are likely to have less status.

The studies by Fawns and Ivanic, Dray and Papen, and Freebody and Freiberg suggest that health literacy, as indicated earlier, is a complex phenomenon that depends on many personal and contextual factors. However, a broader more socially-oriented view of literacy is not only supported by literacy researchers. A recent book, *Advancing health literacy: A Framework for Understanding and Action* (Zarcadoolas et al. 2006), written by three health scientists, suggests that health literacy needs to be conceptualised in a broad way, including attention to community issues, culture and social contexts. This echoes the views of literacy researchers working on health. Another recent article, also from within the medical field (Lurie and Parker 2007), proposes to view health literacy as a community or neighbourhood issue.

Before finishing this section, I would like to point out that when we talk about literacy as a social practice, we do not deny the nature of literacy as the skills of coding and decoding letters, words and sentences (Papen 2005). In relation to health, as a literacy researcher, I do not deny that some health texts are more complicated than others and that it requires literacy skills to be able to decipher and make meaning of such texts. But what allows a patient to make sense of a text and use it for her own benefit does not depend on her literacy ability alone. It depends also on other factors, for example the patient's relationship with the physician, her emotional state, or whether she will be able to draw on others for help. In a sense, a skills view and a social practices view of health literacy (or literacy more generally) can be seen to complement each other, each focusing on different aspects of what happens when we read or write. As explained elsewhere, one highlights the cognitive and technical aspects, the other the social and cultural side of it (see Papen 2005).

5. Linguistics and discourse analysis

A third strand of research in the area of health and literacy covers studies by linguists and discourse analysts. Such research examines the discourses, genres and language of written health information, such as health education materials (Seidel 1990, Wall 2001), pharmaceutical brochures (Coupland and Williams 2002), leaflets instructing patients on specific treatments (Holden 1996) and food labels (Cook and O'Halloran 1999). Other studies have examined media texts such as newspapers (Lupton 1992, 1997,1999; Seale 2001), magazines (Coupland and Williams 2002) and TV shows (Harter and Japp 2001). There are also many studies on conversations between health-care providers and patients (see for example Mishler 1984, Maynard 1991, ten Have 1991, Barry et al. 2001). Some of these have specifically examined power relations between patients and health professionals (Wodak 1996; Roberts and Sarangi 1999, 2002; Candlin 2000).

The above studies on written texts are relevant for research into patients' health literacy, because leaflets, magazines articles, TV programmes as well as internet websites, are the kind of texts patients may be expected to or may want to read. For example, the literacy and ESOL students participating in the Literacy, Learning and Health project held their own views and beliefs about the health matters that concerned them. They drew on a range of written texts as resources to help them make sense of what they experienced and to take decisions regarding courses of action suggested by their doctors (Papen and Walters 2008). In doing so they engaged with 'medical knowledge' passed on to them through the words of physicians and nurses or through written texts. Macdonald (2002) has discussed what happens when 'expert' knowledge is communicated to the patient in the institutional context of the medical encounter. During a consultation, authority is commonly granted to the physician and their expertise, whereas the patient is positioned as the recipient of knowledge. This reminds of the example of the GP and his elderly patient with the headaches mentioned above.

Many health-information leaflets also position patients as in need of instruction. Discourse analysis can show how this is done by using specific grammatical forms or medical jargon. For example, a leaflet might refer to the patient primarily in passive voice: this signals that something is done to the patient or that the patient is the recipient of knowledge and actions. Doctors, by contrast, tend to be referred to in active voice (see Holden 1996, Dray and Papen 2004). In her analysis of publications about the use of patient-information leaflets, Dixon-Woods (2001) identifies what she terms the main 'discourses' about the patient found in education leaflets. What she means by discourses are what views doctors, health-education experts and the designers of such leaflets have about the patient. She distinguishes between a 'patient education' and an 'empowerment' discourse. The patient education discourse sees the patient as passive and receptive to instruction from the medical 'expert'. It is concerned primarily with compliance. By contrast, the 'patient empowerment' discourse promotes informed choice by patients and assumes the patient to be able to handle much more information than the patient education discourse believes. The 'informed patient' discourse (Henwood et al. 2003) is similar to the

empowerment discourse. It believes that the ideal patient is well informed and highly knowledgeable about her disease and can take informed decisions about her health. Understandably, this is much desired. Recent health policies have tried to support better communication between health-care providers and patients in the hope that patients can become more informed. An example is NHS Direct Online, an internet service for patients to find out information about common diseases and their treatment. Whether the ideal of the informed patient can be attained does of course relate to the question of health literacy.

At a more general level, studies such as those by Dixon-Woods, MacDonald, and others cited above are helpful to researchers and practitioners working on health literacy, because they draw our attention to the specific positions and viewpoints contained in patient education leaflets and other texts produced for the lay patient. In the Literacy, Learning and Health project we interviewed literacy and ESOL students about their experiences with information received from doctors or found elsewhere. They told us about leaflets which they had received prior. during or after a consultation and they explained what they had done with them. They mentioned other texts that they had consulted, for example books, magazine articles or internet websites. All these texts carry ideological meanings and culturally informed views, some of which may not match the patient's own individual and cultural background. Patient information leaflets do not simply convey information on certain diseases and their treatment, they reflect medical views on these illnesses and they try to communicate specific and often entrenched ideas about the individual as patient. Wall's (2001) example of breastfeeding discourses is a case in point. These discourses (or viewpoints) explain why breastfeeding is desirable, suggest that mothers should breastfeed and in so doing appeal to new mothers' sense of themselves as wanting the best for their babies. Such views are influential and they can result in women who don't breastfeed feeling bad about themselves as mothers.

As patients, we are subjected to, engage with, accept or reject the views and positions communicated to us in the health-care system. The merit of discourse analytical studies is that they identify and name such positions. Coupland and Williams (2002), for example, identify three discourses about the menopause found in printed media texts: a pharmaceutical discourse (found in pharmaceutical brochures) constructing the menopause as an ailment or disease; an alternative therapy discourse found in popular media texts; and an emancipatory feminist discourse. In the Literacy, Learning and Health project we recognised some of these discourses in our informants' accounts. Alternative therapy discourses, for example, popped up in conversations with patients, mixed with ideas about non-Western treatments. The latter were particularly relevant for understanding how some of our non-British informants dealt with illness and disease. Furthermore, the attention to power and knowledge found in linguistic and discourse analysis helped us to unbury the power relations of medical encounters, which were explicitly mentioned by some of our informants. A sensitivity to power also allowed us to see what role literacy skills played in relation to our study participants' ability to ask questions, voice their concerns and more generally benefit from any information obtained. One of our informants, for example, resented the 'big words' her husband's consultant used when telling them about his diagnosis.

6. Medical sociology and anthropology

Studies in discourse analysis and linguistics, such as those referred to above, partly overlap with work done by medical sociologists and anthropologists. The main difference between the two fields is that linguists and discourse analysts focus their attention more specifically on language (both oral and written) in health-care settings. Sociologists and anthropologists take a broader approach. They examine what is actually happening during a consultation or a specific treatment and how both parties' behaviour is shaped by cultural conventions, institutionally-fixed procedures as well as both actors' social background, education and language. Nevertheless, there is a fair amount of overlap in the questions both disciplines raise and some medical anthropologists have explicitly studied the role of language in health-care interactions (Kuipers 1989). Wall's (2001) already-mentioned study of Canadian educational material on breastfeeding is a good case in point. Being a sociologist, she nevertheless pays close attention to language.

Wall's study also illustrates the tendency amongst many medical sociologists and anthropologists and geographers working on health to foreground the patients' perspective, and to think of health-care systems such as the NHS as cultural spaces (see for example Lazarus 1988, Helman 1994, Gesler and Kearns 2002, Taylor and Field 2003). This makes them appealing to people who are thinking of literacy as social practice and who want to include the context of specific healthcare episodes when trying to understand how particular patients engage with specific health texts. Although this is rarely mentioned explicitly, when we talk about literacy as social practice, we also include the role of culture in our ways of reading and writing. Culture is important in relation to health and health care and this is certainly the case in a multicultural society such as modern Britain. The need to consider how people from different cultural and linguistic backgrounds think and communicate about health and disease, connects work on health literacy to medical anthropologists' interest in the cross-cultural study of medical systems (Kleinman 1978, Good 1994, Sargent and Johnson 1995). By this they mean different medical traditions and how they interact in health-care provision. These may include Western allopathic medicine (what is commonly called biomedicine and which is the dominant form of treatment in Britain), homeopathy, Indian medicine or psychology.

7. Conclusions: Gaps in the existing literature

In the previous sections, the contributions of four fields of research to our understanding of health literacy were summarised. Each field has its own perspective and priorities. Medical scientists and health educators are primarily concerned with how health practitioners can identify patients who struggle with written information and what can be done to help them. Research in this area focuses on developing tools to assess people's health literacy and ways of measuring the complexity of health texts such as patient education leaflets. Literacy studies, the second field of research discussed, investigate the situational nature of reading and writing. Literacy researchers look at health literacy not in terms of the skills people theoretically have, but they try to understand the specific situations in which patients engage with health texts. They look at health literacy in contexts of use. Literacy researchers tend to concentrate on what people do with a specific text - how they use it. By contrast, linguists and discourse analysts examine the text itself in detail. By analysing their linguistic features, they try to identify how texts are likely to be read and interpreted. We can see that literacy researchers and discourse analysts come to health literacy from different but complementary perspectives. Finally, medical anthropologists and medical sociologists have a lot in common with the two previous fields. Like literacy researchers, they look at the social and personal context of health and health care. Like discourse analysts, many of them are interested in power relations and the role of the institutional context. Their focus however is broader, looking not at language specifically but at communication and social interaction in a broader sense.

The above summary and commentary on academic research in the field of health and literacy shows that there is relatively little qualitative research on lay people's (patients') strategies to access, comprehend and use the written information they receive from health-care providers (see, however, two brief chapters by Rudd 2004 and Rudd et al. 2004). The majority of studies are quantitative, based on surveys and tests. There is little in-depth research about the difficulties people with poor basic skills experience in dealing with the health-care system. The Literacy, Learning and Health project that my colleague Sue Walters and myself have conducted is hoping to fill some of these gaps (for a detailed report of our findings see Papen and Walters 2008). But many other studies are needed to improve our understanding of what health literacy is and what it means for patients in health-care contexts.

8. The relevance of academic research on health literacy for teaching and learning

Academic research is not always of direct relevance to practitioners. Its merit may be more in how it can inform the general perspectives of those working in the practice. The above literature review shows that academic studies have much to say about the links between literacy and health generally and about how we can identify and measure what health literacy is. These insights can be useful to practitioners both in the health field as well as in adult literacy. For the present purpose, I will only comment on the possible relevance of these studies for literacy, numeracy and ESOL teachers. They may find that the broad social and cultural understanding of health literacy (proposed by literacy researchers as well as some health scientists) resonates with what they know about how their own students deal with ill health and the skills demands of health care. Thinking about health literacy in broad terms can also sensitise them to the diversity of people's reading and writing abilities and to the importance of the context. General education levels or literacy tests, as mentioned already, offer indications of how a person might engage with a piece of written information. But a broader view of literacy allows us to pay more attention to the contextual factors that explain people's behaviour or performance. This would, for example, include knowledge of the specific moment a leaflet is read, what prior information (for example from the doctor) the recipient has had and who might be around when it is read. The latter point is particularly important because many people share literacy tasks and literacy skills therefore don't only reside in individuals but in groups of people, for example families. In that sense, a person's literacy can be seen to go beyond her own skills (Maddox 2007). For literacy practitioners this means that supporting people's ability to draw on others for help with their literacy needs could be a goal of their teaching.

Research by discourse analysts can also be of interest for literacy practitioners. The use of 'critical language awareness' (Fairclough 1992) in adult literacy is not new, but is particularly relevant in the age of a World Wide Web that offers endless information, not all of which is reliable or of a high quality. Literacy teachers could use patient education leaflets as part of their teaching to support awareness of how texts are constructed – what grammar, words, phrases and images they use – and to help users of such texts learn how to 'read between the lines' and discover the positions and ideologies conveyed through such texts.

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Notes

1 The literature search was carried out by Susan Dray, Sue Walters and myself. We covered the following databases: Academic Search Premier, JSTOR (an archive of scholarly journals), Linguistic and Language Behaviour Abstracts, Blackwell Synergy, PsychINFO, MEDLINE and Web of Science. We browsed these using the key word 'health literacy'. We also tried other keywords, for example 'health information' and 'health education'. These produced a large number of publications, but it was difficult to ascertain whether these were relevant and it was impossible for us to read them all.

2 The project, which was funded by the NRDC, spanned over a period of two years and eight months, beginning in late 2003. We recruited participants from literacy and ESOL classes across the North-West and Yorkshire. At the time of the research, some suffered from specific illnesses and were undergoing treatment. Others recalled their previous experiences with doctors, nurses and other health care providers. Unless the student objected to it, the interviews were taped and fully transcribed. We collected additional data through informal conversations with the 44 students. Five of them agreed to get more closely involved in our study and were interviewed repeatedly. I thank the NRDC for supporting this research.