

Literacy, learning and health – a social practices view of health literacy

Introduction

The social practice view of literacy (see above), also known as the ‘New Literacy Studies’ (NLS) has been used as a framework to study literacy in a range of everyday settings (see for example Barton and Hamilton 1998, Jones 2000, Fawns and Ivanic 2001, Papen 2007). The primary objective of these studies is to investigate what people do with literacy in real life contexts rather than to assess how good they are at reading and writing in a testing situation. Nevertheless, many researchers adhering to a social practices view of literacy are interested in the educational implications of their studies. In Britain, researchers close to the NLS have challenged dominant literacy policies (see for example Crowther, Hamilton and Tett 2001, Papen 2005). 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 which are most relevant to their own experiences (Barton et al. 2004). Health is one such topic. Many adult learners suffer from health problems and they are interested in learning about health and lifestyle issues (Papen and Walters 2005).

Links between ill health and low levels of education are widely acknowledged. Until recently, however, adult literacy policy in Britain has paid little attention to the topic of health and almost no research existed that explored the relationship between patients’ level of literacy and their ability to assess and benefit from health services. In the past five years this has changed and there is now growing interest amongst researchers and politicians, both from the field of adult education and health, to explore measures to support people’s ‘health literacy’ (Baker et al. 1999). Work in the US and Canada has inspired these efforts and it is often believed that Britain can learn from programmes and initiatives developed in North America. Overall, the interest in health literacy is practice-oriented. Research into existing forms and levels of health literacy is part of this, but it tends to take the form of small and quick studies, their main aim being to support the development of measures to teach patients better health literacy (see for example the national ‘Skilled for Health Demonstration Programme’, <http://www.dfes.gov.uk/readwriteplus> and the *National Health Literacy Collaboration*, a new initiative by the Department for Health.)

The study ‘Literacy, Learning and Health’ is an exception to this preference for applied or action-research. It is also one of the few studies that apply a social practices view to the area of health literacy (for others see for example Freebody and Freiberg 1999). The overall aim of this study that spanned over a period of 2 years and 8 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. The study participants were learners in adult literacy and ESOL (English for Speakers of Other Languages) classes across the North West of England. 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.

The dominant view of health literacy is that it can be defined as an abstract skill

which can be measured through individual performance tests. Such tests examine patients' ability to understand specific texts (such as patient information leaflets) and their familiarity with medical terminology (see for example Davis et al. 1991; Parker, Williams and Nurss 1995; Moon et al. 1995; Baker et al. 1999)). Interestingly, the two most used tests were both 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).

But what do these tests really measure? Few if any researchers appear to have asked these questions. Clinicians and health educators accept them, either because they believe in them or because they are the only scores available. So are there no alternatives to 'testing' people's health literacy? The study 'Literacy, learning and health' started from the assumption that there are indeed other ways of exploring people's ways of reading and writing in relation to their health. To begin with, we talked about health literacy 'practices' rather than health literacy 'skills'. Discarding the notion of skills, we were able to 'explore' or 'investigate' 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 didn't define those as narrow skills. Rather we conceptualised them as broad competencies, some of which, as we found out, were not located in individuals but in groups and social networks. Our research methodology was guided by the principles of ethnography. We started simply by asking people about their experiences with health-related tests. Interviews were open-ended and mostly unstructured, the intention being to collect detailed accounts of people's dealing with health care providers, their experiences of texts such as forms, prescriptions and package inserts and their strategies to access and understand health information. Difficulties and struggles, without us prompting them, were frequently part of people's accounts. Yet, we also heard many stories of what people did to overcome their problems. We were told of how a woman who had had several miscarriages learned to search the internet for insights into what had happened to her and how an elderly patient relied on her son to help her type out a list of all her medication. These narratives 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.

Open-ended interviews with 44 literacy and ESOL students present the bulk of the data gathered. In addition, we have data from participant observations in health care settings. Furthermore, we have 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.

Key findings and issues emerging from our research

First of all, our research has revealed that many health care processes are 'textually mediated' thus requiring the patient to engage with various sorts of written texts. But patients also need to speak and to listen and dealing with written texts is often part of a speech event. The kind of language (spoken and written) used in health care contexts is frequently specialist and patients are often being told about complex medical procedures. Understanding such procedures and how they are described by

medical personnel does not only pose challenges for literacy and ESOL students or others who are seen to have low basic skills. The technical language of modern medicine is challenging for any non-specialist or lay person.

Literacy and ESOL students, including those commonly represented as having significant basic education deficits, may experience significant gaps in their health literacy. But this does not mean that they have no resources and strategies when it comes to dealing with the literacy and language demands of health care settings. In our study we found that health literacy is often 'distributed'. By this we mean that it is not simply a property or an attribute of an individual (who is assumed to have a certain level of health literacy). Health literacy is shared knowledge and understanding, it resides in the family, the neighbourhood and the social network of a patient. 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.

Furthermore, we found that health literacy is always 'situated' or 'contextual'. It should not be seen as an abstract attribute or a generic ability of the mind (as something a person does or does not possess), but as what is happening in a specific moment of health care and what the patient is or is not able to achieve at that time. This means that if we want to understand patients' health literacy, we need to take account of the broader context of their experience as patients and more generally as people being ill. In order to achieve this, we have included in our study the context of health care itself: what our informants have told us about the practices and processes of dispensing health care in England, for example what happened when they met with doctors, when medication was prescribed, how a specific medical procedure was carried out and when and how they were notified of its results. In so doing, we have looked at specific health literacy practices, such as reading a leaflet, not in isolation, but as part of a longer process of what we call a health care episode – the time period over which our informants were dealing with a particular symptom or disease. We have placed the specific moment of engaging with a particular text (for example coming back from a visit to the surgery and reading a leaflet received from a doctor) in the context of such an episode. This allowed us to take account of our 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. Finally, we have placed particular emphasis on our informants' personal context and social networks and on the way they draw on others, be they family members or friends, to deal with illness and its emotional effects. It is our assertion that in order to understand a patient's health literacy all these factors have to be taken account of. Only then can we shift our attention away from the patients' assumed skills deficits to their meaning-making abilities and practices. 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 and are able to achieve.

A further important finding is that health literacy includes dealing with social relationships that are hierarchical (doctor-patient) and which frequently disempower the patient who is at the receiving end of health information and health care practice. The aim of health literacy cannot be simply to achieve compliance, e.g. to make patients do what their doctors want. Patients want to take their own decisions and while these may frequently coincide with the doctor's advice, this does not always need to be the case.

Finally, health literacy also includes emotional aspects: dealing with information not only on a cognitive but an affective level. Several of our respondents spoke about the fear they felt when learning about a serious disease. One couple talked about their reluctance to read a leaflet containing details of the chemotherapy the husband was to undergo. These responses show that health literacy is about more than skills.

To conclude, the finding of our study challenge narrow ideas of health literacy as a measurable and abstract concept. They cast doubt on the validity of any pronouncements of patients' health literacy based on test results. Tests such as REALM (Gordon et al. 1999) neglect the contextual nature of reading and writing in health care contexts and the power issues involved in modern health care practice. They also ignore the many ways in which patients, including those believed to have low levels of basic education, access and comprehend health information, make sense of their experience and the resources they draw on.

Implications for policy and practice

The implications of the 'Literacy, Learning and Health' study for literacy and health policies in Britain are manifold. First and foremost, as explained already, the study challenges dominant conceptions of health literacy. A broader concept of health literacy, taking account of contextual and emotional issues, power relationships, practices and existing resources is needed. Adult literacy classes that use health as a topic need to start with learners' own experiences and with their existing knowledge and understanding. Ethnographic-type research into students' own health literacy practices, carried out by students themselves, not by professional researchers, should be a central component of the curriculum. Any teaching of health literacy needs to be based on the findings of such research. More generally, the results of our research suggest that existing initiatives to develop embedded or integrated literacy and health classes are a promising way forward. Such initiatives should best be focused on specific diseases or lifestyle issues. However, 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. Instead, we suggest health/literacy classes for specific audiences (e.g. women of a certain age group).

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