"Bad" Literacy, the Internet, and the Limits of Patient Empowerment

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Abstract

The growth of health literacy and patient empowerment movements has resulted in a more active and prominent role for patients as autonomous actors in decisions relating to their health. The Internet has become an important source of information for patients seeking to understand their health conditions and to evaluate possible treatments. However, in making autonomous healthcare decisions, the Internet can be viewed by patients as a decision support system. The Internet is poorly adapted to this task and may lead patients to make hasty, ill-informed, and even dangerous health choices. It is important, therefore, to guide patients to approach the Internet with appropriate skepticism and to temper their perceptions of autonomy.

Both patient empowerment and health literacy have been advocated as important to increased patient well-being. Empowerment, viewed as the autonomous involvement of patients in healthcare decisions, has been promoted on at least three grounds. Patient advocates take a normative stance--promoting increased participation by patients in health decision making as a matter of right, arguing for increased personal autonomy through more egalitarian structures and more equitable distribution of power between practitioners and patients (Bhopal and White 1993; Sherwin 1992). Health policy analysts favor patient empowerment as a means for citizens to take responsibility for their healthcare in order to control healthcare costs (Neuhauser 2003). Healthcare professionals have taken an interest in empowering patients to improve health outcomes (Edwards, Davies, and Edwards 2008), but while they often recognize the potential benefits of patient empowerment, they also raise concerns about the ability and motivation of patients to engage appropriately in health decision making so as to realize those benefits.

This concern for ability has been the focus of attention in the study of health literacy. Health literacy focuses on "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." Most studies of health literacy focus on basic skills including reading comprehension and numeracy, particularly among at-risk populations such as those with limited education, recent immigrants with limited English skills, and the aged whose cognitive as well as physical abilities may be compromised. However, if the goal is greater self-sufficiency, a literate health consumer needs skills beyond these basics. Nutbeam, for example, distinguishes basic or functional literacy from communicative/interactive literacy and critical literacy, which invoke skills that allow the person to derive meaning from available information and to use that information to exercise greater control of and responsibility for his or her health (Nutbeam 2000). These skills might include declarative knowledge, e.g. information about health and medicine, procedural knowledge, i.e. rules guiding reasoned choice about the proper course of action, and finally judgmental skills (Schulz and Nakamoto 2005). In order to participate in the manner envisioned for an expert patient, the person would need judgmental skills relating knowledge to his or her experiences and goals.

If the primary goals of empowerment are efficiency and improved outcomes, then literacy (in all its forms) is an essential foundation. "Patients are empowered when they have the knowledge, skills, attitudes, and self-awareness necessary to influence their own behavior and that of others … to improve the quality of their lives" (Funnell et al. 1991). Consider, for example, successful examples of programs designed to improve health outcomes through patient empowerment relating to chronic diseases like diabetes (Anderson and Funnell 2010). The idea of the "expert patient," which has emerged recently in UK health policy, describes a patient who is well informed or has access to crucial information regarding his or her own health conditions (Wilson 2001). This information is held

to allow patients to become responsible for their own health, including activities such as recognizing their own symptoms, managing acute episodes, using medications, interacting with healthcare providers, seeking information and using community resources (Fox, Ward, and O'Rourke 2005). In other words, empowerment entails the ability of the patient to make health-enhancing choices deriving from knowledge and expertise.

The Limits of Literacy

Implicit in the desirability of increased patient literacy is a critical assumption—that patient education (and thus literacy) will improve patient decisions. The present debate on health literacy hardly ever raises the issue of the limits of patient education. Limits and deficiencies of patient education have been considered in areas in which the physician is obliged to inform a patient sufficiently, especially when information has to be provided on the effects and side effects of a particular treatment envisioned and suggested by the physician. Obligatory patient education, however, is not without problems. In some situations, it is even conceivable that providing detailed obligatory information is at odds with medical intentions of a therapy. For it may be that the precise and complete provision of information makes a patient interrupt or cancel a therapy that is beneficial to him.

The Internet raises a different problem of literacy. It makes available to the patient a vast array of information, and beyond information, websites that offer advice, promote products and services, and even provide formal tools that seek to assist patients and consumers in making healthcare and health maintenance decisions. This enables patients to use the Internet independently as a decision support tool. In this role, however, the Internet suffers from serious limitations, the most obvious being inaccurate information. However, even accurate information can create problems for patients who are not capable of using the information appropriately.

Despite the growth of "tailoring" of information to individualize its applicability, much of the information available on the Internet is general. For example, promotional websites for prescription medications, like the mass media advertising for these products, speak of the health condition the medication is designed to treat, the benefits of use, method of use, and information on potential side effects. The information is not universal (most side effects are rare) but neither is it tailored. The medications are not suitable for all patients and even when they are, they will not be effective for all patients. However, it is rare that any calibration of the probabilities of effectiveness, particularly with respect to specific groups of patients (children versus adults, for example), is presented.

Furthermore, increasing the amount of information is incapable of enabling patients to handle this information adequately. Ever more comprehensive patient "education" is likely to remain incomplete for fundamental reasons. The utility of health information depends (as is the case for all information) on the recipient's background knowledge that is necessary for understanding the new information and evaluating it adequately. That understanding and evaluation can only have an impact on behavior when it is verbalized in the form of statements. But these statements build on a background that is composed of the variety of forms of non-declarative knowledge. This unobjectifiable knowledge normally occurs in the form of individual dispositions such as experience specific to a field or the ability to assess situations adequately. It is this form of knowledge that constitutes the background before which related information has to be understood and considered in behavioral decisions.

The importance of such background knowledge for the understanding of information, for instance in the field of health, is generally underestimated. It is therefore often overlooked that information, as detailed as it may be, is placed before a different background when it is related to a patient, compared to when it is related to an expert. Both a physician and a website can offer a patient nothing but objectified information. Background information that determines a patient's competence in the area and helps to assess information adequately must be assumed by the provider. Of course, a good website may consider the limited capability for understanding medical knowledge and the patients' background knowledge, and accordingly aim at making itself understood by the patients it wants to educate. But only a patient's level of information can be affected, not his background knowledge. This is, of course, the essential difference between the physician and the patient. The expertise arising from extensive medical training is a background against which the specifics of a patient can be interpreted to develop a diagnosis and treatment plan.

The patient's unique expertise is in the specifics of their symptoms, their experience of the health condition, and their health goals. A problem arises when a patient receives information that she cannot assess adequately. Several studies conclude that patients in these cases make an effort to insert the information into their dispositional background knowledge anyway, and also bring it into concordance with their goals and wishes. Given the flexibility of the Internet, treating it as a decision support device presents serious dangers.

The Internet: Failures in Decision Support

Decision support systems offer a number of important advantages (Murray and Häubl 2008; Pick 2008; Udo and Guimaraes 1994) First, they help to insure that an adequate range of decision criteria are considered. Second, they enforce some level of consistency in the way the salient information is applied. Viewing a decision schematically, they do this by constraining the decision procedure, preventing cognitive "short-cuts" that ignore critical considerations. An additional value of a decision support system can be the embodiment of best practice within the system, so that past experience can be brought to bear on a decision problem. Learning systems can take this a step further by using the individual's interactions with the system as a basis for improving the system's ability to guide and respond to the individual's needs and desires.

As a decision support, the Internet is not only ill-constituted for the task but its flexibility makes it dangerous. Rather than enforcing a systematic approach to a decision, a search engine will likely encourage the user in pursuing shortcuts that ignore critical considerations. The patient's own preferences, wishes, and predilections will govern information search, exacerbating any pre-existing biases. Even when the decision is novel, Meloy et al. show that, as preference judgments are being formed, initial leanings during the decision process lead decision makers to focus information search on supportive data, making the final choice self-fulfilling.

A true state of ignorance with no prior preferences is no better. In this case, information search will be not random but driven by the commercial interests that make some information more accessible as those sites first in the search list. In other words, rather than internal biases driving decision, here external ones may be overly influential.

In this sense, the Internet can promote unintentional misuse of information—that is, bad literacy, a case in which more knowledge leads to worse decisions because it leads the patient as decision maker to bias information search to reinforce the self-serving cognitive biases that afflict their decisions or become cognitively "trapped" by commercial persuasion.

Coherence in Literacy and Empowerment

Analyses of health literacy and of patient empowerment often entangle the concepts. It is important first to distinguish two visions of patient empowerment. First, empowerment can refer to the institutional arrangements that enable a patient to be more autonomous in their health management. A physician, for example, may instruct the hospital nursing staff to allow the patient latitude in the amount of pain medication taken after surgery. This approach will be central in considering policy implication.

Second, empowerment can refer to the psychological feelings of power, control, and self-esteem that lead the patient to value autonomy—and thus interest in and desire to participate in healthcare decisions. In this vein, patient empowerment is volitional and involves the patient not as a passive recipient of information whose task is comprehension and acceptance but as an active processor of information extracting self-relevant meaning from proffered information and advice and choosing and enacting behaviors he or she believes appropriate to the health situation (Morgen and Bookman 1988; Rissel 1994; Wallerstein 1992). The benefits of empowerment in this version generally assume that the patient has the requisite expertise to participate effectively in decision making.

Similarly, studies of health literacy often assume that an informed or expert patient will be empowered in the psychological sense. That is, work on health literacy regularly takes empowerment as a goal but seems to take for granted that high levels of expertise will naturally lead to effective self-management. However, as shown in Figure 1, specific attention to literacy and empowerment as independent constructs is critical to improved health outcomes.

		Psychological Empowerment	
		Low	High
Health Literacy	Low	High-needs Patient	Dangerous Self-manager
	High	Needlessly Dependent Patient	Effective Self-manager

Figure 1: Literacy, Empowerment, and Patient Behavior

The idealized vision of advocates of both improved health literacy and patient empowerment is to move people from the upper left cell of the figure to the lower right one—helping high-needs patients to become effective self-managers of their health using healthcare resources appropriately to optimize their health outcomes. The need to consider both literacy and empowerment can be seen in the other two cells. A psychologically empowered patient who assumes an authoritative role in his or her healthcare decisions lacking adequate knowledge and skill could well make dangerous choices that impede his or her health goals. Highly literate people lacking in psychological empowerment may choose to be highly dependent on health professionals despite their ability to make well-informed decisions for themselves incurring needless cost.

This distinction highlights the need for guidance in patient use of the Internet as a decision aid or, more generally, the careful design of patient empowering institutional arrangements. Certainly, guiding patients to information

that is both relevant and accurate is important. However, particularly for chronic health conditions, it will be valuable to improve the patient's background knowledge—i.e., to guide the development of greater health literacy.

The Internet and Empowerment

As noted earlier, literacy must involve more than simply the ability to read and count. For example, if a Type 2 diabetic is to be able to participate meaningfully in health decisions, literacy also implies:

- a base of accurate declarative (factual) knowledge such as the relation between bodyweight and insulin resistance;
- domain-specific procedural ("how-to") knowledge such as how to maintain a healthy bodyweight through calorie and carbohydrate restriction and exercise;
- judgment skills that allows the patient to relate knowledge to his or her goals, particularly in novel situations, such as choosing to contact the doctor when there is a change in health status (e.g., blurred vision).

It is in this realm of improving health literacy that the Internet provides a wealth of resources. But even here, structure is critical. Machine learning tools for commercial advice like those oriented to shopping rely on generalized preferences. Given that you have sought information of this type or bought certain items, others like you also looked at or bought other specific goods.

In the case of improving health literacy, this approach could lead to the same self-fulfilling decision problems noted earlier—leading a patient to build a knowledge structure oriented to their wishes rather than reality. The knowledge would be consistent and coherent but incomplete and dangerously biased. Not just a single decision but all decisions would build on this bad literacy.

The implication is that tools tailoring information and seeking to support patient literacy cannot be neutral collections of data. Institutional arrangements to empower patients cannot mean a "hands-off" policy or allowing the patient unconstrained freedom. It is critical to guide the development of health literacy based on evidence-based principles and to empower patients through active engagement. A first step in that direction could be the creation of websites that, rather than pretending or suggesting to support medical decisions, make an effort to relate the criteria that have to be considered in such a decision, with the aim in view to teach patients that such decisions are vastly complex. The decision to prescribe hypertension medication, for instance, would have to be detailed into (1) the decision to treat the condition by medication or other measures (improved diet, exercise, etc.), (2) the decision to

prescribe a particular type of medication (ACE inhibitors, Angiotensin II receptor antagonists, beta blockers, etc.) and (3) the decision to choose a particular drug. By listing all factors that have to be considered in these decisions an appropriately complex picture would be created that may potentially make patients discard easy answers and learn that it is not for them to make these decisions alone.

Conclusion

Drawing a distinction between literacy and volitional empowerment highlights the importance of appropriate background knowledge if patients are to participate meaningfully in health decisions. The engineering of this background knowledge—guided literacy—presents new challenges for health professionals and web content providers. However, efforts to tailor information and "meet patients where they are" cannot be neutral. While proponents of patient empowerment may campaign against an ideology of "medicalization," the implications of that position are dangerous. Evidence-based judgments, however imperfect, incomplete, or unpleasant, are the essence of empowered patient decisions.

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