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Barriers to Health Information and Building Solutions

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Abstract

Most stakeholders in the health care system—doctors, patients, and policy makers—have not been taught to apply evidence-based information to the many decisions that must be made daily. Little awareness of this problem exists, yet a better use of evidence could improve outcomes for patients, increase patient satisfaction, and lower costs. This chapter considers how the use of information that emerges from evidence-based medicine could be improved.

"Health literacy" constitutes the first step. After a discussion of the barriers that exist to health literacy (e.g., lack of incentive to search for health information, non-standardized reporting of health results, and poor comprehension), possible remedies are presented. Raising health literacy by targeting individual stakeholder groups, such as patients and health care professionals, is debated as is the option of focusing on change in the overall health system. What is required to achieve a change both at the individual and system levels? Solutions are unlikely to generate systemic changes in center-based treatment variations. However, a change at one level may set off change in another. Finally, increasing awareness beyond the immediate professional community is necessary if systemic changes are to be made. The promotion of health literacy requires careful consideration to reach the various stakeholders throughout the health care system.

Introduction

Health literacy is a broad, social concept. The Institute of Medicine (IOM 2004) defines it as "the degree to which individuals can obtain, process, and understand basic health information and services they need to make appropriate health decisions." Statistical literacy can be interpreted as the ability to grasp the meaning of numbers, proportions, and probabilities. However, although statistical competency is important, it is not the essential component

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in health information. This was recognized by the World Health Organization, which included social competencies and skills into its definition of health literacy (WHO 2010): "Health literacy has been defined as the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health."

To appreciate the complexity of health literacy, it is important to realize that it is not a static concept. Experiences in personal health, the health care system, as well as cultural and societal influences all shape a person's ability to obtain, process, and understand basic health information. Zarcadoolas, Pleasant, and Greer (2006:5–6) advocate a broader view of health literacy, which they define as "the wide range of skills, and competencies that people develop over their lifetimes to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life." They specify four different domains of health literacy:

1. Fundamental literacy includes the traditional view of literacy according to the IOM definition.
2. Science literacy means that a stakeholder appreciates fundamental scientific concepts and processes, and understands that technological relationships are often complex and can rapidly change. They also understand that there is an inherent element of uncertainty to the scientific process. Zarcadoolas et al. (2006) suggest that only between 5–15% of the general public are scientifically literate.
3. Civic literacy covers the domains of information acquisition and information source. Specifically, civic literate individuals are able to judge the information source as credible, possess media literacy skills, have a basic knowledge of civic and governmental systems, and are also aware that personal behaviors can affect the community at large.
4. Cultural literacy includes the ability to recognize, understand, and use the collective beliefs, customs, world view, and social identity of diverse individuals. Cultural literate individuals are capable of interpreting and acting on cultural information and context, and are aware that certain information can only be interpreted through a cultural lens.

This expanded concept has profound implications when constructing appropriate messages intended to be understood easily by health literate individuals. Clearly, the use of plain language and simple numbers is not enough; the broader civic and cultural context must also be considered.

Steckelberg et al. (2007, 2009) suggest that teaching competencies that enhance consumers' autonomy in health care issues requires combining the concepts of evidence-based medicine, evidence-based health care, and health literacy. Competencies originating from this new concept are referred to as *critical health literacy*. Some aspects are absent from existing definitions (e.g., the information that patients are not receiving and their ability to request such information). Patients need to know how to pose questions and to be suspicious when, for example, a brochure specifies the benefits of a drug or treatment but neglects to list possible harms or the merits of alternative routes of action. Indeed, everyone exposed to health information should be able to pose questions as to the knowledge source and its bias.

We suggest that definitions of health literacy apply to all stakeholders. The levels at which any one particular stakeholder needs to obtain, process, and understand information will obviously vary, as will the specific area of focus. However, all stakeholders can be included in a definition if the extent of the knowledge to be obtained, processed, and comprehended depends on whoever is pursuing it. Notably, differences will exist not only between but also within stakeholder categories; information should be available so that individuals can choose how much or how little of it they need.

For the clinician, information must be obtained from the patient: What are the patient's preferences, life circumstances, and history? Once elicited, this information should be used to establish the alternatives which the professional presents and recommends. It is the clinician's responsibility to communicate health information to a patient and to ensure its comprehension. Improving skills to obtain, process, and understand patient-specific information remains a challenge.

For journalists, policy makers, and public communicators, health information must be conveyed so that the patient, reader, consumer, or citizen understands it. However, this must be done without compromising the evidence base. When communicating to the general public, journalists, policy makers, or public communicators must consider the potential hurdles that their stories or accounts will invoke and help the public overcome these. Reports need to be intelligible, though not at the cost of accuracy.

Existing definitions of health literacy have focused on the individual person—primarily the patient. They take into account the individual's ability and skills, yet ignore elements that could influence and help the individual understand and interpret medical information. Some of these factors are internal, such as the patient's beliefs and their impact on comprehension. Others are broader in context: cultural and social aspects, or even the extent to which health literacy is pursued. The way systems are structured affects a patient's ability to obtain, process, and understand health information. If such information exists only in specialized journals, if it is presented in an incomplete manner, if media reports sensationalize it or omit "boring" details (e.g., sample size or numbers needed to treat), then obtaining, processing, and understanding health information is greatly impaired. Focusing on any stakeholder at the individual level may not be the most beneficial way of promoting health literacy.

We suggest a dual approach: top down and bottom up. We discuss remedies at the individual level, but also at the level of the information as conveyed throughout the health system and beyond, including industry and government.

Obtaining, Processing, and Understanding Health Information

In an ideal world, society would be made up of health literate citizens, yet this is not the case. Here we discuss potential barriers that exist to hinder the process of accessing health information. Not every obstacle will be easy to overcome. Still, there is value in drawing attention to them so that their impact can be addressed in the future.

Social Construction of Roles

The chain of events whereby a person sets out to obtain information requires motivation. A person who is content with the information they have is unlikely to contemplate obtaining further knowledge. People need to feel unsettled and be urged into actively seeking information. While acquiring new knowledge requires action on the part of an individual, the motivation to do so does not solely stem from the individual. Motivation can involve a shift in the way society constructs the “sick” role; that is, whether a patient is a mere recipient of information or someone who assumes an active role in health-related decision making, including the decision of whether to engage with the medical establishment. Such construction of prevailing narratives has been shown to be influential in selecting treatment options (Wong and King 2008). Likewise, for health care professionals, it would be conducive to health literacy if greater emphasis were put on reflective practice. The active pursuit of information by a patient does not necessarily equate to an inherent mistrust of health care professionals, but is often perceived as such. This needs to be addressed in the role construction of both the patient and health care professional.

Perceiving Information Seeking as Mistrust in Health Care Professionals

If patients and other stakeholders perceive information seeking as a sign of mistrust, they might be reluctant to engage in this behavior or to encourage others to do so. The misinterpretation of trust as blind acceptance is most often imposed on patients, though it may apply to other stakeholders as well. Those who provide information often struggle with numbers or may have conflict of interest. Thus, blind trust in the health care professional who presents information can be a barrier to health literacy.

Onora O’Neill argues that trust has fallen dramatically in many institutions: “Mistrust and suspicion have spread across all areas of life” (O’Neill 2002:8). The usual answer to the growth in mistrust is to insist on transparency and greater accountability in everything. Further, O’Neill argues that “if we want to restore trust we need to reduce deceptions and lies….well placed trust grows out of active inquiry, not blind acceptance” (O’Neill 2002:70, 76).

One would hope that health care professionals and other stakeholders, who are sometimes mistrusted, would view the opportunity to refer patients to information they can check and assess themselves as advantageous rather than

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threatening. For example, Nannenga et al. (2009) demonstrated that a decision aid designed to help patients decide about statin use was associated with both increased knowledge and enhanced trust on the part of patients. Trust increased with patient participation.

David Mechanic (2004) reminds us that patients cannot always assess their health care professionals' skills, which then leads to trust or mistrust accordingly. He mentions other bases for trust, however, which coincides with the notion of professionals both conveying information and eliciting patient-specific input: "Patients' trust is how doctors communicate and whether they listen and are caring. Patients do not expect intimacy but they do seek respect and responsiveness…patients want to know that their doctors are committed to protecting their interests" (Mechanic 2004:1419).

Paternalism

When health care professionals, policy makers, insurers, or other stakeholders avoid presenting evidence to patients, decline to share uncertainty, and/or make decisions on their behalf, they erect barriers to health literacy. Paternalism supports the notion of a patient as a passive, non-inquisitive recipient of whatever information the professional wishes to impart. Health professionals may do this with the best of intentions, believing that it actually protects patients, as has been the traditional style of doctors for centuries. Yet increasingly, doctors do share evidence and uncertainty with patients. Unfortunately, many health care professionals continue to insist that patients do not want to share in the decision-making process. It is undoubtedly true that some will choose, under some circumstances, to allow health care professionals to make decisions on their behalf, but strong evidence indicates that doctors assume all too often a paternalistic attitude (Stevenson et al. 2004; Coulter and Jenkinson 2005). Professionals should adopt a default position that patients want to be informed and, at the very least, should ask patients how much information they would like and whether they would like to share in the decision-making process.

Paternalism is not confined, however, to the doctor–patient encounter. It is evident between the media and the public, the government and the public, and health care professionals and policy makers.

Perceived Inadequacy in Handling Medical Information

A de-motivating factor for seeking health information is the feeling that even if accessible, it will not be understood. In a study on prostate cancer patients (van Tol-Geerdink et al. 2006), about half of the patients (69 of 148) indicated an initial low preference to participate in medical decisions. However, after receiving information about treatment options from a decision aid, 75% of these patients wanted to be involved in choosing their radiation dosage. Contrast this with the group of patients who expressed an initial high participation preference, where 85% wanted to be involved in choosing their radiation dose.

This suggests that although patients may have initially refrained from seeking information or making health decisions, preferring to defer to professional opinion instead, once information is available in a clear and understandable way, these same patients now feel equipped to participate in decision making.

Barriers to Obtaining Health Information

Lack of Evidence-based Information

Although there is an abundance of communication on health issues targeting patients and the general public, it rarely adheres to criteria deemed by researchers as necessary for making decisions on health issues (Bunge et al. 2010; Steckelberg et al. 2005; Trevena et al. 2006). Information must be relevant to the individual patient, its content must be based on the best available evidence, and its presentation must follow specific criteria to allow understanding of the information. Elements that are often missing include quantitative estimates of the benefits and harms of treatment options, diagnostic or screening procedures using numbers, and verbal and graphical presentations. All options should be presented, including the option not to intervene or to postpone the intervention. Outcomes relevant for patients should be reported rather than surrogates. At present, such information is provided only for a few areas of interest; structures are missing to ensure that updated, comprehensive, and understandable information can be used by all stakeholders.

Non-standardized Reporting

It is difficult to develop the skills to seek out health information if such information is not reported in a consistent form. Clear, transparent templates need to be developed and consistently utilized: in textbooks, drug information, patient brochures, newspaper reports, and white papers. Standardized reporting is also a key component in the development of a scheme to address existing and missing knowledge.

Existing and Missing Knowledge

To pursue information, one needs a scheme involving the kind of information that is needed within a particular decision situation. If such a scheme is absent, one does not know what is missing, or even that the information they are receiving is incomplete. An overview of questions to ask, to know what information must be sought, has been provided by Gigerenzer et al. (2007). These questions can serve as informal guidelines for designing risk information.

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Listed below are some of the most important questions and concepts that need to be clarified when examining health information.

- Risk of what? Does the outcome refer to dying from the disease, not getting the disease, or developing a symptom?
- What is the time frame? Time frames such as the “next ten years” are easier to imagine than the widely used “lifetime” risks. They are also more informative because risks can change over time but ten years may be long enough to enable action to be taken. For example, for every thousand female nonsmokers (age 50), 37 will die within the next ten years; however, for every thousand smokers (age 50), 69 will die (Woloshin et al. 2008).
- How big? Since there are few zero risks, size matters. Size should be expressed as absolute rather than relative risks.
- Benefits and harms: Screening tests, as well as treatments, have benefits and harms. Thus information on both is needed. Always ask for absolute risks of outcomes with and without treatment.
- Screening tests can make two errors: false positives as well as false negatives. Understand how to translate specificities, sensitivities, and other conditional probabilities into natural frequencies. Ask how common the condition is in the population: Out of 1,000 sick people, how many will the test correctly identify (sensitivity) and how many will it miss (false negative rate)? Out of 1,000 healthy people, how many will the test correctly identify (specificity), and how many will it mistake as ill (false positive rate)?

Conflicts of Interest

A conflict of interest occurs when an individual or organization is involved in multiple interests, one of which could possibly influence the other. A conflict of interest can only exist if a person or testimony is entrusted with some impartiality. Thus, a modicum of trust is necessary to create it.

An Institute of Medicine report on the topic states that “conflicts of interest threaten the integrity of scientific investigations” (Lo and Field 2009:2), and “evidence suggests that...relationships [between industry and researchers] have risks, including decreased openness in the sharing of data and findings and the withholding of negative results” (Lo and Field 2009:9). However, the authors are also explicit in saying that empirical evidence is limited and that “data are suggestive rather than definitive” (Lo and Field 2009:4).

In 2001, American-based pharmaceutical companies sent out some 88,000 sales representatives to doctors’ offices to hand out nearly US$11 billion worth of “free samples” as well as personal gifts (Angell 2004; Chin 2002). The expectation is that when the free samples run out, doctors and patients will continue to prescribe or take them. An editorial in *USA Today* (2002) painted a vivid picture: "Christmas trees; free tickets to a Washington Redskin game, with a champagne reception thrown in; a family vacation in Hawaii; and wads of cash. Such gifts would trigger a big red "bribery" alert in the mind of just about any public official or government contractor."

Even though the Office of the Inspector General of the U.S. Department of Health and Human Services issued a warning in 2003 that excessive gift-giving to doctors could be prosecuted under the Anti-Kickback Law, critics stress that the laws are still full of loopholes (Angell 2004). In recognition of these pervasive influences, some major hospitals in the United States have denied pharmaceutical representatives entry onto their premises and have forbidden the sponsoring of meals where products are advocated. In addition, existing conflict of interest regulations have been tightened to enforce strict reporting of any incomes or stock holdings of health care-related companies, of hospital employees, as well as their family members. It is too soon to tell whether these efforts have been effective in curbing the influence of the pharmaceutical industry on health care delivery.

Alongside health care professionals, patient advocacy groups also meet the criteria for assumed impartiality. Such groups have become a target of the industry's marketing efforts (Grill 2007) and have been found to be strongly entangled with pharmaceutical companies, who often design their web sites and pay their public relations agencies (Angell 2004). Company representatives sometimes even take leading positions on their boards (Schubert and Glaeske 2006). Such entanglement may cloud any objective view of a pharmaceutical product portfolio and prevent doctors' and patients' advocacy groups from either requesting or reporting transparent numbers on the real benefits and harms of a drug or medical intervention. In general, little is known about the exact extent of influence that pharmaceutical promotions have on the behavior of patient advocacy groups.

Barriers to Processing Health Information

During elementary, middle, and high school education, children are seldom taught risk, probability, and the concept of uncertainty. This lack of education is at the root of the prevailing levels of low statistical literacy. Teaching schoolchildren how to approach frequencies and probabilities helps prepare them for the complexities and uncertainties of the modern world; it also equips them to make sound decisions throughout their lives (Bond 2009; Gigerenzer et al. 2007). Yet the attainment of these necessary skills is not part of the curricula in every school and in every country.

Health statistics and randomized trials are an indispensable part of clinical practice. In 1937, an editorial in *The Lancet* stressed the importance of statistics for both laboratory and clinical medicine, and criticized the "educational blind spot" of physicians. In 1948, the British Medical Association Curriculum

Committee recommended that statistics be included in medical education. Ten lectures were proposed with additional time for exercises, ranging from teaching core concepts such as chance and probability to interpreting correlations (Altman and Bland 1991). Despite this, it took until 1975 before statistics became a mandatory subject in medical schools within the University of London, and it took an additional ten years before adoption in Austria, Hungary, and Italy (Altman and Bland 1991). Although statistics has received a mandatory status, statistics and risk communication are far from being an essential part of medical education: Only 3% of the questions asked in the exam for certification by the American Board of Internal Medicine cover the understanding of medical statistics (clinical epidemiology), and risk communication is not addressed at all. Similarly, biostatistics and clinical epidemiology do not seem to exceed the benchmark of 3% in curricula of medical schools, and transparent risk communication is completely lacking (cf. Wegwarth and Gigerenzer, this volume). Another important aspect in improving literacy is an understanding of what information is missing. For example, in the case of screening, does the report include numbers needed to treat, does it include health outcomes of control groups that have not received screening, and does it include information on potential harms? If society wishes to have literate doctors, medical schools need to devote time in their curricula to teach the concepts of transparent and nontransparent statistics, as well as which information is necessary and which is not. Teaching medical students transparent representations fosters understanding (Hoffrage et al. 2000) and so does teaching doctors (Gigerenzer et al. 2007). Every medical school should require graduates to exhibit at least minimal statistical literacy, with a longer-term goal of requiring more advanced understanding.

Barriers to Understanding Health Information

There are transparent and nontransparent formats for statistical information. Much of the mental confusion that defines nontransparency seems to be caused by the reference class to which a health statistic applies (Gigerenzer and Edwards 2003). Single-event probabilities, by definition, specify no classes of events, and relative risks often refer to a reference class that is different from the one of which a patient is a member. Sensitivities and specificities are conditional on two different reference classes (patients with disease and patients without disease), whereas natural frequencies all refer to the same reference class (all patients). Survival and mortality rates differ crucially in their denominator; that is, the class of events to which they refer. Clarity about the reference class to which a health statistic refers is one of the central tools in attaining health literacy.

Understanding could also be improved by providing numbers as well as words. Patients have the right to know the extent of the benefits and harms

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of a treatment, and qualitative risk terms are notoriously unclear. Contrary to popular belief, studies report that a majority of patients do prefer numerical information to care alone (Hallowell et al. 1997; Wallsten et al. 1993). Providing patients with accurate, balanced, and accessible data on disease risk and treatment benefits could, however, influence their choices in ways that doctors may consider undesirable. Patients may be very surprised at how negligible many of the risks or benefits are. Consequently, they may dismiss interventions that physicians might deem extremely valuable.

In one example, participants in a study were very optimistic about the effectiveness of three different drugs; in each case, these perceptions dropped substantially after seeing the actual data (Woloshin et al. 2004). This was a cause for concern, since one of the drugs—a statin used to treat men with high cholesterol but no prior myocardial infarction—showed a reduction of overall mortality over five years from 4 in 100 patients to 3 in 100 patients. It seemed that many respondents did not appreciate the real magnitude of this effect. Few drugs now being manufactured can match this reduction in all-cause mortality among relatively healthy outpatients.

To judge how well a drug (or other intervention) works, people need a context; that is, some sense of the magnitude of the benefit of other interventions. Reactions to benefit data will change as people have more exposure to them. Consumers will be better able to discriminate among drugs and interventions as they become better calibrated to effect sizes. This context is necessary so that people do not discount small but important effects.

How Can Stakeholders Be Motivated to Obtain Good Quality Evidence?

We live in an era where knowledge abounds and time is pressing. Assuming that a general practitioner needs only five minutes to skim an academic article, it has been estimated that 600 hours per month are required to read all of the published academic items pertinent to primary care alone (Alper et al. 2004). Work on cognitive limitations and information overload leads us to question whether simply providing more information will result in a higher comprehension levels (Shaughnessy et al. 1994). Clearly, the existence of information is not enough. For information to be utilized, it needs to be deemed useful, a concept Shaughnessy et al. defined as:

$$\text{usefulness} = \frac{\text{relevance} \times \text{validity}}{\text{time required to obtain}}.$$

While clinicians often claim that they consult medical journals or the library when they are unsure how to proceed, research suggests they may actually consult with their colleagues instead (Shaughnessy et al. 1994). This clearly fulfills the requirements of efficiency and relevance (a sense of local practice norms may also be a source of reassurance to the anxious practitioner), but the information may not be of the highest quality.

It has proved challenging to develop systems capable of ensuring that information is relevant at the point of delivery. Even when there are attempts to make clinical advice context dependent (e.g., notifications on evidence in practitioners' computer systems, like EMIS), these may be deactivated by practitioners, who regard them as intrusive or unhelpful. A system that sets red flags, when several medications prescribed to the same patient are determined algorithmically to be incompatible, may be disenabled if it raises alerts so as to be overwhelming. Thus too much information, given in an automated and unsolicited way, may not be the ideal structure.

Humans are good at judging relevance. "Information prescriptions," given explicitly by health care practitioners to patients, provide an example and could be improved by considering when the information is most relevant. For example, it may be most useful for people to have access to information contextualizing a discussion with a clinician before an appointment, requiring that information prescriptions are routinely sent out in anticipation of an appointment, and ensuring that such information exists. The concept of alerting patients to a range of treatment options prior to meeting with clinicians is the subject of research in shared decision making. At the Decision Laboratory (2010) in Cardiff University, parents of children referred for possible tonsillectomy are sent a checklist, based on a national guideline, which stipulates the criteria for surgery. Parents are asked to assess whether their child meets these criteria. The impact of this checklist is being evaluated.

Guessing what consumers of information will find relevant, however, is not enough: the information needs to be evidence based. Most decision support systems assume that patients would like to know, for example, the probability of suffering a heart attack with different treatments over a one- and five-year period. Thus, decision support systems are designed to answer these questions, even though they may not be the ones that a patient asks. Some support systems do present patients with alternatives in vivid terms. The Prostate Interactive Education System (PIES 2010), for example, displays the harms and benefits of prostate cancer treatments in film format, using real doctors.

An individual's own search activities provide a valuable source of information and may prove the most valuable resource. Similarly, just as we must identify areas of clinical uncertainty to drive the generation of primary and secondary research (trials and systematic reviews), we may need to consider systems to identify where there is the most need for the evidence-based information.

Good quality evidence-based information should be available online. Ideally, such information needs to be organized rationally, preferably in a standardized format, and accessible with consistent search tools. The Finnish Medical Society, Duodecim, has been producing national evidence-based current care guidelines since 1995. This web-based tool is administered by expert groups, who select core clinical questions to be answered; systematic literature searches are conducted, articles critically appraised and summarized, and detailed evidence reviews linked to the text as background documents. Guidelines also include a patient version and an English summary. Ninety-eight guidelines are available from a single web site (Current Care 2010) free of charge. In 2004, physicians accessed 3.2 million articles from this database; this corresponds to each Finnish physician reading one guideline per working day (Kunnamo and Jousimaa 2004). In 2009, the number of annual readings had reached 12 million, which means that health professionals consult the guidelines four times per day on average (Jousimaa, pers. comm.). This statistic is encouraging; it indicates that when up to date, standardized information is accessed by people who need it, when they need it.

Standardized Reports and Common Health Literacy Vocabulary

Non-standardized reporting impairs comprehension as well as health literacy by increasing the risk that flawed or misleading reporting can become accepted as the truth. If we could develop a prototype of a transparent and comprehensive report, information transfer might be optimized and health literacy might be more easily attained. Due to the nature of reporting, meeting this goal will not be easy. However, unless we impose a structure in this complex and rapidly changing field, the framing and transfer of information will continue to be unnecessarily difficult.

We deliberately interpret the term *reports* loosely. We envisage standardized reporting in (a) professional medical journals and subsequent press releases; (b) newspaper stories, feature articles, commercials, or advertisements; (c) patient communications (e.g., brochures, support-group web sites, or mammogram screening invitations); and (d) official documents intended for policy makers, commissioners, insurers, and other major players. In terms of medical content, our suggestions relate to individual decisions, whether concerning treatment, prevention, or diagnostics, as well as to population decisions regarding public health interventions.

Are There Precedents?

Whether discussing an intervention, screening or diagnostic test, or even a recommended behavior change, information needs to be presented and clearly delineated so that any stakeholder can weigh the possible benefits and harms. At a minimum, these can be listed and informally weighted. Often there is sufficient evidence to quantify the likelihood of specific benefits and harms. In our discussion of how these "probabilities" might be displayed, we reviewed several suggestions for conveying information in a stratified, standardized fashion (for a review, see Politi et al. 2007).

The Cochrane Collaboration utilizes a layered structure in its reports and has developed a plain-language summary, which includes the use of numbers. The inclusion of a "summary of findings" table for the main comparison in the review is gradually becoming the standard (Schünemann et al. 2008). Cochrane appears to believe that this does not compromise the quality of their reports and has positively evaluated the format. Cochrane has standardized as many elements of the reports as possible (Higgins and Green 2009); for example, although the effect of the intervention may be reported as an odds ratio, the absolute risks with and without the intervention are reported as frequencies (with the same denominator used throughout the report). Both "high" and "low" baseline risks are considered, and "GRADE" assessments (GRADE Working Group 2004) of the quality of evidence are provided for each benefit and harm.

Review users often become overwhelmed when more than seven outcomes are presented; more than this is confusing and cannot be integrated. Thus, in line with memory constraints, Cochrane Tables list no more than seven benefits and harms (or, more commonly, outcomes) (Higgins and Green 2009). These are ordered by degree of benefit, followed by potential harms. Cochrane also includes a "plain language summary" intended for patients, but accessible to all (Higgins and Green 2009, Chapter 11).

In Germany, guidelines are presented at three levels: a short version (no numbers) for doctors, a longer version (with numbers) for doctors, and a version for patients that includes practical suggestions (e.g., what to do if you are at particular coronary risk and feeling unwell: should you rush to the hospital or wait until the morning). The German Disease Management Guidelines (NVL 2010) also includes an evaluation of the quality of the evidence; this transparency allows clients to be critical users of the information.

The "drug facts box" is another clear example of a successful precedent. Developed by Schwartz and Woloshin (this volume), its goal is to provide accurate information on prescription drugs to the public. By utilizing a standardized 1-page table format, it summarizes the benefits and side-effect data on prescription drugs in a concise manner. Descriptive information about the drug is provided: its indication, who might consider taking it, who should not take it, recommended testing or monitoring, and other things to consider doing to achieve the same goals as the drug.

How Can Statistical Information Best Be Presented?

We suggest that this can best be achieved by combining the strengths of the "drugs facts box" (Schwartz and Woloshin, this volume) and the "summary of findings table" (Schünemann et al. 2008) using a layered format and a vocabulary accessible to all stakeholders. Principles for "basic" representation are as follows:

1. Represent probabilities as whole numbers using a constant denominator (e.g., 1000). Probabilities could also be shown as miniature icons representing people.
2. Provide a list of probabilities with and without intervention (as two columns) to allow comparison between options. The difference between interventions could then be presented in a third column.
3. Include harms and benefits.
4. Reproduce tables for different baseline risks (but do not include relative risks).
5. Include an indicator of quality of evidence (but do not include confidence intervals in the basic presentation).
6. Provide a common format for patients, health care professionals, policy makers, and the media.
7. Encourage an electronic version, with links to supplemental information for those sufficiently motivated. This would allow multiple graphical formats, animations, resources, references, etc., depending on the desires and sophistication of the user.

These principles will not apply in all circumstances, but are intended to spur further development. The challenge and goal for the future will be to develop standardized reporting formats for qualitative as well as for diagnostic research.

Who Can Help Make Standardized Reporting Happen?

Multiple strategies—both bottom up and top down—are necessary to implement standardized reporting. It will never be enough to embed it within guidelines alone, since guidelines are often not adhered to or enforced.

The U.K. Academy of Medical Sciences is proposing uniform requirements for reporting benefits and harms in medical journals. There is already an expanded CONSORT statement to include harms (Ioannidis et al. 2004), but no evidence on compliance. Editors and referees of peer-reviewed and other journals are best positioned to ensure adherence to guidelines. We note, however, that editors in the mass media may lose influence if publishing continues along its present trajectory. Continuing medical education (CME), or an equivalent professional organization for journalists, could help disseminate the prescribed reporting formats, should editors become obsolete.

In line with the mandate to provide patients with helpful, agenda-free information, patient advocacy groups could help enforce implementation. Some major charitable organizations (e.g., the U.S. National Breast Cancer Coalition) already present information in this way.

The pharmaceutical industry provides another avenue, since it is in their interest to make clear the balance of harms and benefits. Hormone replacement therapy information leaflets provide current examples of risk reporting. Paradoxically, this is one place where legislators can mandate the ways information needs to be presented. Even if a company cannot list all alternatives to their proposed product, they could be required to note the efficacy of their treatment compared with a placebo or no treatment, as is the case in the drug facts box.

A model by which good practice can be enforced may be found in Finland. There, a consumer organization reviews every type of patient-oriented communication according to pre-determined and well-publicized criteria, and either grants or withholds its stamp of approval.

Standardized reporting could also be enforced through a bottom-up approach. If consumers are trained in reading statistics (when these are provided in natural frequency format) and become familiar with a standard format, we can expect that they will, in turn, demand that information is presented in this way—be it from the media, industry or other source. Trained citizens would not be susceptible, for example, newspaper stories consisting solely of relative risk information and, likewise, would be wary of advertisements devoid of information on numbers-needed-to-treat. Equipped with the necessary tools and skills, informed consumers will be able to demand better, clearer, more transparent information from their physicians, media, and others.

What Could Stop Standardized Reporting from Happening?

We should expect the call for standardizing report formats to be met by objections. One possible source could come from health care professionals, who might perceive that standardized information (and patient aids) would interfere with their professional judgment—making them obsolete or turning them into automatons. Yet there is a big difference between presenting numbers clearly and implementation. Accessible information to the patient makes the doctor’s role all the more crucial: doctors will be able to discuss implications and patient-specific recommendations, rather than regurgitate information already available. Rather than debilitating, doctors should view this change as emancipating and enabling. Standardized reporting does not eliminate health care professionals; it simplifies and streamlines the processing and understanding of information, thus leaving room for more substantial discussions to take place.

Another objection concerns the modification to original data, which involves judgment. Take the Cochrane list of harms and benefits for example: Who determines the importance of each of these? A reasonable way to address such objections is to make the judgment process transparent. In addition, the multi-layered presentation used allows anyone to go back to the original paper or raw data to generate their own impressions and ratings.

Inevitably, various groups and stakeholders have agendas and would prefer to select information to coincide with their interests. Thus, it is imperative for the public to become trained in reading standardized reports to detect information gaps and distortions.

Improving Health Literacy Skills

In this section, we discuss different ways to improve public comprehension of health information. Our ideas are not comprehensive, but serve to highlight areas which should be further explored.

Targeting Young People

The need to change existing educational school curricula to promote statistical literacy throughout the population has been discussed elsewhere (e.g., Gaissmaier and Gigerenzer; Smith, this volume). Early statistical teaching must overcome the assumptions that the mathematics of certainty (e.g., algebra and geometry) is more important than the mathematics of uncertainty. Martignon and Kurz-Milcke (2006) provide an encouraging study that shows the effectiveness of early training: fourth graders were able to master combined probabilities after participating in structured games using colorful cubes.

While structured education offers one method, another avenue might be through computer and board games. Games appeal to young people and could be an appropriate platform to turn something that appears difficult to understand into something that is assimilated naturally. For example, in the United Kingdom, computer games designed to teach probabilities have utilized aspects of gambling and have proven to be very appealing to young people (Spiegelhalter 2010). At a later age, visualization software such as Fathom (Finzer and Erickson 2006) and TinkerPlots (Konold and Miller 2005) help young people explore and manipulate data sets (Garfield and Ben-Zvi 2007). By starting with concrete representations of risks, children can accumulate confidence in basic concepts and will less likely develop a math phobia when more complex concepts are introduced at a later stage.

Although computer probability games for children exist already on several Internet sites, the extent to which young people take advantage of these games is unknown. Use of those designed explicitly for children, such as Club Penguin (2010) or Webkinz (2010) provides a starting point to incorporate modules to teach probability. These popular resources often have modules geared toward spelling, have attractive designs, and award children points for successful performance. Providing incentives to commercial companies to integrate relevant modules into resources widely used may be a feasible means of reaching and capturing the attention of children.

Another example can be drawn from a curriculum of critical health literacy for secondary school students, age 17 years, successfully piloted by Steckelberg et al. (2009). The curriculum's objectives were to develop and enhance statistical knowledge and competencies, to appraise medical information critically, and to gain understanding of how medical information is developed.

From Patients to Doctors

Simple decision aids for interpreting the meaning of medical test results provide a possible means of educating patients. Human mediators (e.g., health coaches who inform patients on how to pose questions about the benefits and risks of tests administered by their physicians) might also facilitate access to health information.

Increasingly, patients' interests are being represented on health care boards, agencies, and institutions. Training courses for patient and consumer representatives to cope with these roles have been successfully piloted (Berger et al. 2010).

Computer games that involve probability might help health care consumers, medical students, and clinicians explain the benefits and risks of various tests and screening instruments to their patients. In addition, handheld devices (e.g., touch phones) could be equipped with probability guides so that medical students and clinicians can calculate key measures (e.g., base rates of diseases, frequencies of medical conditions, and the absolute risk of having a disease after testing positive) or access information to key questions.

A more direct route to medical students would be through the Medical College Admission Test (MCAT), which is administered by the American Association of Medical Colleges (AAMC). Since every prospective medical student is required to take the MCATs, there is high motivation to perform well. Thus, if probability, uncertainty, and other core concepts of statistical literacy were integrated into the exam, students would be motivated to acquire this competency. As with children's computer games, the trick is getting people to want to know.

Journalists

Journalists exert a powerful influence on how the public perceives health and health care. Much of what people—including many physicians—know and believe about medicine comes from the print and broadcast media. Yet journalism schools tend to teach everything except the understanding of numbers. Journalists generally receive no training in how to interpret or present medical research (Kees 2002). Medical journals communicate with the media through press releases; ideally, they provide journalists with an opportunity to get their facts right. Unfortunately, press releases suffer from many of the same problems noted above (Woloshin and Schwartz 2002). Some newspapers have begun to promote correct and transparent reporting, and efforts are underway to teach journalists how to understand what the numbers mean. As in Finland, statistical training courses for journalists exist at several universities and are conducted by some government agencies. Opportunities for statistical learning remain rare in the media, however.

Editors play a central and powerful role in the presentation of new stories, at least in traditional media outlets. Even a minimal amount of training for editors (e.g., knowing which questions to ask about statistical procedures in health and medical studies written by reporters) could improve general news coverage.

Another push to make journalists report more carefully about medical facts could come from statistically literate observers. Internet sites in the United States and Australia, for instance, rate the quality of medical reporters and medical news in major news publications. One such site (Health News Review 2010) evaluates the quality of health reporting in major U.S. newspapers and magazines. Although this form of watchdog effort has not yet been evaluated, it seems plausible to assume that by intensifying the monitoring of press coverage of medical statistics, improved reporting will result.

Change from Within

It is difficult to define the level at which change should be pursued. It is people who understand information, but the problem neither starts nor ends at the individual level. Should the focus be on the patient and his/her maladies, history, and choices? Or should the emphasis be on the policy maker who determines funding, resource allocations, treatments, screenings, and bed numbers for millions?

The best way to change a system is from within. Those who set health policy and fund health care are in the strongest position to ensure that more health promotion and care is based firmly on evidence, that formats are standardized, and that people are helped and encouraged to obtain, process, and understand evidence.

There is strong evidence to indicate that the amount of health care that people receive is largely determined by the supply of health care institutions (i.e., "supplier-induced demand") (Fisher et al. 2004). For example, people in Los Angeles receive twice as much health care as people in Minneapolis simply because there are twice as many health care providers in Los Angeles. Far from producing benefit this leads to increased adverse outcomes Los Angeles: people are more likely to suffer from errors that are common in the health system because they come into contact with it more often. Wennberg (pers. comm.) argues that improving health literacy among the people of Los Angeles is unlikely to reduce the amount of care they receive. Yet providing his compelling data to those who organize and fund health care could potentially reduce the health care supply in Los Angeles and encourage care based on evidence.

Do We Need to Demonstrate the Benefits of Health Literacy?

In a room full of psychologists and physicians who have been practicing shared decision making for decades, the benefits of health literacy appear obvious. Yet, this skill is neither prevalent nor actively fostered by most major players in the health and education arena. To promote health literacy, especially if this endeavor entails a major change in the way risks, benefits, and probabilities are conveyed in every report, we need to transmit the merits of health literacy beyond the scope of its current advocates. Presently, two main justifications exist for promoting health literacy, representing two different viewpoints that are not necessarily contradictory. We discuss these benefits (ethical and economic) in turn. The widespread exploitation of this lack of literacy through biased report of evidence can also be seen as a moral issue (see Gigerenzer and Gray, this volume).

Improving Health Literacy: An Ethical Imperative

Since the Age of Enlightenment, efforts have focused on educating citizens for their personal and the greater societal good. It has become an ethical obligation to educate young members of society. Over time, general educational efforts have been applied to health issues: individuals' knowledge about diseases, risks to health, and ways to maintain a healthy lifestyle. Yet, health literacy levels, as defined previously, have generally been found to be insufficient among large segments of the population. A recent report by the American Medical Association (AMA) estimates that over 89 million American adults have limited health literacy skills (Weiss 2007). This estimate is based on the AMA's interpretation of the results of a National Assessment of Adult Literacy survey conducted in 2003, wherein AMA reclassified anyone "below basic" or "basic" (Weiss 2007:10) health literacy as being "limited" and multiplied this percentage by the number of adults in the population.

To address this remarkably low level of literacy, efforts to increase health literacy have been advocated as a necessary condition for a better educated population—one capable of making appropriate and informed health decisions and engaging in recommended health behaviors. Increasing health literacy has even been called an ethical imperative for health care professionals, who are tasked with ensuring that individuals process and comprehend relevant public health messages, treatment options, and recommended regimens (Gazmararian et al. 2005; Woloshin and Schwartz 2002).

Improving Health Literacy: A Means of Reducing Costs and Improving Care

In the present era of cost containment, it is questionable whether the ethical imperative is sufficient to remedy the dismal situation of low literacy levels and to develop and sustain the resources for an effective health literacy campaign. One argument put forth by the AMA is that individuals with limited health literacy incur up to four times greater cost in unnecessary doctor visits and hospital care, compared to individuals with average health literacy.

Increasing health literacy has been associated with a number of positive outcomes: improved decision making, better understanding of disease and treatment regimens, and adherence to prescribed treatment options. It is thus possible that increased health literacy could translate to lower costs associated with increased adherence and fewer unnecessary doctor visits and hospitalizations. Indeed, studies on the health outcomes of low-income individuals (controlling for education, insurance, race/ethnicity, sex, language, insurance, depressive symptoms, social support, diabetes education, treatment regimen, and diabetes duration) have found that those with higher health literacy had better health outcomes than those in the low literacy group (Schillinger et al. 2002).

However, the assessments of detailed costs are hampered by the fact that multiple outcomes could be considered and standards for assessments do not exist. The question therefore arises as to how outcomes can best be measured.

What Are the Most Appropriate Outcome Measures?

A number of outcomes have been associated with improved health literacy. For example, adherence to diabetes treatment regimens (Mühlhauser and Berger 2002) increased after patients received an intervention designed to improve understanding of the disease and self-management of its treatment. Other outcomes frequently mentioned are the reduction of unnecessary care and its associated monetary savings. Another measure, which resides between the ethical imperative and economic benefit, is that of quality of life. If health literacy is associated with reducing the severity of chronic diseases (e.g., diabetes or hypertension), patients' lives may become more bearable and acute outcomes can be avoided.

Marketing Implications: Promoting Systemic Change

There is a strong sense that psychologists and health care professionals have valuable health literacy tools and information which are underused. If we assume that a need exists among stakeholders in the health domain for obtaining, processing and understanding information, we can state that our products, as it were, address a pressing need. That this need is seldom met, or even identified, by stakeholders is a problem that could be solved through improved coordination and marketing.

Marketing is a word rarely used in the world of health literacy. However, drug companies, diagnostic tool manufacturers, and other commercial players use appealing strategies to promote their information. Often, their products do not represent the totality of the evidence in the most readily comprehensible fashion, and yet they are widely and efficiently disseminated. Evidence-based patient information and evidence-based information sources targeted at health care professionals compete in the ideas market alongside these materials.

In marketing our insights, knowledge, and tools, we have several resources at our deposal. The public and clinicians have considerable trust in academics and other health care professionals. Several strategies are available to us to exploit this receptiveness. Just as individual case studies of patients may be appealing, case studies of clinicians who had a positive experience around improved health literacy may be helpful in marketing (e.g., positive experiences in shared decision making, improved statistical literacy). As the media is often drawn to stories of personal interest, we could attempt to create such stories demonstrating, for example, how a city, a school, or a retirement home achieved better health outcomes due to a literacy intervention. There are publication venues for these positive stories in "personal view" sections of professional journals, and these could be written or solicited by anyone in the field.

For resources to be obtained, they need to be easily accessed. To date, however, there is no single information resource linking all the many available decision aids and risk calculators. At the most basic level, a Wikipedia page could be created, producing background references and a table of available tools. It would be trivial—yet surprisingly novel—to install a piece of wiki software on a server such as "decisionscommons.com" where trusted and registered academics in the field could update a central structured list of resources. The same could readily be done for structured and updatable lists of educational resources, probability games for children, and other resources.

A top-down approach also needs to be applied, as change cannot only come from below. Lobbying politicians to improve the quality and transparency of patient information provided by industry may bear fruit. Sites funded by the state (e.g., NHS Choices 2010) also represent good examples of state-funded, patient-facing, evidence-based information. Another strategy would be to offer assistance in developing statistical features to add into existing online communities and games. This will require funding and infrastructure but would be extremely helpful in reaching audiences far beyond what conventional interventions can accomplish.

"Translational medicine" or the concept of knowledge translation (Davis et al. 2003) is a relatively new principle which is also relevant here. Generally characterized as taking research work "from the laboratory to the bedside," it improves the application of basic science research to clinical research and practice (Lean et al. 2008). At its simplest level, it may be beneficial for all who work in the field to keep in mind that their work could be applied when communicated in professional and lay media.

In all of these actions, there is a strong argument to have a single professional organization for those engaged in improving health literacy: one that will reflect the interests of the community; act as a central contact point for clinicians, academics, journalists, politicians, civil servants, and patients seeking further information and expertise; coordinate lobbying; fund outreach activities and share information. Such an organization would also serve as a valuable resource for generating and sharing ideas on promoting the field of health literacy, in addition to this early and speculative list.

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