

Target Article

Health Literacy, Health Inequality and a Just Healthcare System

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Limited health literacy is a pervasive and independent risk factor for poor health outcomes. Despite decades of reports exhibiting that the healthcare system is overly complex, unneeded complexity remains commonplace and endangers the lives of patients, especially those with limited health literacy. In this article, we define *health literacy* and describe the empirical evidence associating health literacy and poor health outcomes. We recast the issue of poor health literacy from within the ethical perspective of the least well-off and argue that poor health outcomes deriving from limited health literacy ought to be understood as a fundamental injustice of the healthcare system. We offer three proposals that attempt to rectify this injustice, including: universal precautions that presume limited health literacy for all healthcare users; expanded use of technology supported communication; and clinical incentives that account for limited health literacy.

Keywords: Health Literacy; health disparities; justice; health policy; health outcomes; pay for performance

Approximately 90 million American adults lack the literacy skills needed to use the healthcare system (Nielsen-Bohlman et al. 2004). The prevalence of limited literacy is particularly high among those with lower levels of education, the elderly, minorities, and those with chronic disease (Paasche-Orlow et al. 2005b). An emerging literature has begun to describe the myriad health consequences of limited literacy (DeWalt et al. 2004). Indeed, limited literacy has been shown to be an independent risk factor for worse health status, hospitalization and mortality (DeWalt et al. 2004; Sudore et al. 2006b; Wolf 2006a). Though more than 300 articles in the medical literature exhibit ways healthcare is overly complex for people with limited literacy, the recent shift toward shared decision-making, consumer-oriented healthcare and programs such as Medicare Part D are evidence of increasing complexity (Parker et al. 2003). Despite the clear injustice of a healthcare system that is organized for the most literate and powerful members of our society, the medical ethics literature has neglected some of our most vulnerable patients by remaining largely quiet about the ethical implications of health literacy.

In this article, we will define *health literacy*, a concept closely linked to literacy, and briefly review the empirical evidence for the association between health literacy and poor health outcomes. Then we will explore the moral implications of limited health literacy for a healthcare system based on justice using one influential criterion, the position of the least well-off. Finally, we will offer three proposals to address this basic injustice. Our hope is that these ideas will bring greater attention to a significant limitation in the current healthcare system and that instigating a far-reaching

discourse on the moral implications of the emerging literature on health literacy may help lead to amelioration of this source of basic inequalities in health.

HEALTH LITERACY AND HEALTH OUTCOMES

Health literacy is the “degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions” (Nielsen-Bohlman et al. 2004, 4). While basic literacy skills, such as reading, arithmetic and using documents are core attributes of the broader concept, health literacy also includes skills such as: how to use the healthcare system; having cognitive dimensions such as memory and attention; and, displaying adequate neurosensory capacities such as vision and hearing (Baker 2006). Another key feature of the definition is that health literacy highlights the contextual demands placed on the individual. Many people who experience literacy barriers would not experience such limitations if the healthcare system were to be streamlined, simplified and standardized (Paasche-Orlow et al. 2006).

Health literacy may be a critical and underexamined mechanism of health inequalities (Saha 2006; Sentell and Halpin 2006). Limited health literacy has been shown to be a more powerful predictor of health status and health-related behaviors than race or education (Baker et al. 1997; Bennett et al. 1998; Scott et al. 2002; Williams et al. 1998a; Williams et al. 1998b). Furthermore, limited health literacy has been shown to be an independent risk factor of worse outcomes and health disparities independent of race and education

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(Baker et al. 1998; Baker et al. 2002; Paasche-Orlow et al. 2005a; Sudore et al. 2006b; Wolf et al. 2006b).

Limited health literacy is associated with low health knowledge, increased incidence of chronic illness, poorer intermediate disease markers and less than optimal use of preventive health services (Berkman et al. 2004). Numerous studies have exhibited the association between limited health literacy and health outcomes; in two separate studies, limited health literacy has been linked with mortality (DeWalt et al. 2004; Sudore et al. 2006b; Wolf et al. 2006a). For example, in a community sample of 2,512 men and women age 70 to 79 years, Sudore et al. (2006b) found that, over the course of a mean follow-up of 5.1 years, those with limited health literacy had a higher risk of death than those with adequate literacy (19.7% versus 10.6%, respectively). In other words, the rate of death for those with limited health literacy was approximately twice the rate of death among those with adequate literacy (hazard ratio of 2.03; 95% confidence interval 1.62 to 2.55).

Furthermore, in the same study (Sudore et al. 2006b), after adjusting for age, race, gender, income, education, health status, health behaviors, health access, and psychosocial status, health literacy remained an independent risk factor for all-cause mortality with a hazard ratio of 1.75 (95% confidence interval 1.27 to 2.41). To put the size of this effect into context, Malik et al. (2004) found that having diabetes conferred a 1.97 (95% confidence interval 1.59 to 2.43) adjusted hazard ratio for all-cause mortality among 6,255 subjects with an average of 13.4 years of follow-up in the Second National Health and Nutrition Examination Survey (NHANES II), i.e., the health impact of having limited health literacy is on the order of having diabetes.

Justice and Healthcare

Previous critiques of the high literacy demands of the healthcare system have focused primarily on the issue of autonomy. For example, attention has been paid to the overwhelming complexity of informed consent forms and efforts have been made to simplify the consent process in ways that are successful with patients who have limited literacy skills (Paasche-Orlow et al. 2003; Sudore et al. 2006a). The autonomy of healthcare users with limited literacy is thwarted if the forms intended to preserve their individual autonomy are inaccessible.

While concern for patient autonomy is well placed, a more thorough evaluation of the moral consequences of limited health literacy can be assessed through an analysis of the requirements of justice. The complexity of the healthcare system negatively affects the health of people with limited literacy, and much of this complexity is unneeded. The lens of justice helps focus the discussion on how this unneeded complexity and the general assumption of high literacy skills influence health and promote racial and ethnic health disparities. While it is inappropriate to ignore patients' values and preferences, and cynical to ignore opportunities to advance patient autonomy by improving patient education materials, consent forms, notices of privacy pro-

tection (Paasche-Orlow et al. 2005c), patient's bill of rights documents (Paasche-Orlow 2006), and the like, we believe the problem of limited health literacy should primarily be understood as an issue of health inequality and justice.

One widely used criterion for examining the role of justice in health inequalities is the position of the least well-off in a healthcare system (Daniels 1985; Rawls 1971). Presently, the healthcare system places little importance on the position of the least well-off in the context of health literacy. The average English reading level for American adults is between the eighth and ninth grade; the average reading level of many documents designed for patients, including education materials, explanations of benefits and services, and documents outlining patients' rights such as informed consent forms, notices of privacy protection, and advanced directives documentation, continue to be written at the senior high-school level or higher (Paasche-Orlow et al. 2003; Paasche-Orlow et al. 2005c; Paasche-Orlow 2006). Despite the fact that one in three users of the healthcare system has limited literacy, a high level of literacy is typically assumed and the healthcare system remains fit only for users with the highest literacy.

The primacy and importance of the position of the least well-off in any healthcare system has been an influential criterion for evaluating the justice of a healthcare system, especially in theories of distributive justice. The position of the least well-off more generally has been a common thread in numerous religious philosophies and most closely associated with the ethical theory of prioritarianism (Parfit 1991). Previous uses of this principle in the healthcare context stem from the widely influential maximin principle found in the philosophical and economics literature, most notably in the work of the philosopher John Rawls (1971). In Rawls' framework, decision-makers, who are behind a veil of ignorance and unaware of their positions in a society, would design a system in which the position of the least well-off is maximized regardless of the potentially negative impact on those better off (Rawls 1971). In the healthcare context, decision-makers using the maximin principle would design a system that places the least fortunate healthcare users in the least unfortunate situation. For decision-makers considering the least well-off in terms of health literacy, the most just arrangement would be one that ensured that the healthcare system was designed to benefit users with limited literacy.

The reorganization of healthcare to fulfill the prioritarian objectives raised in discussions of health literacy would involve the elevation of patient education to be a core function of health providers. Instead of assuming literacy and then trying to retrofit care for low literacy patients as some form of specialty service, application of the maximin principle leads us to the conclusion that the standard of care should be reoriented to the needs of health consumers with limited literacy. In the remaining sections, we will explore three examples of how efforts in clinical care and health policy can help shift the standard of care to make the needs of patients with limited literacy a priority and begin to

address the fundamental injustice arising from an unnecessarily complex healthcare system.

UNIVERSAL PRECAUTIONS FOR LIMITED HEALTH LITERACY

Presently, the standard of care or default position of physicians commencing discussions with patients is to assume a high level of literacy. Limited health literacy is some kind of exception to the rule, and patient education is contingent on a patient asking for more information. Indeed, physicians rarely evaluate comprehension (Schillinger et al. 2003; Schillinger et al. 2004). Patients are trained to say that they understand everything clearly when clinicians inquire about questions while rising from a chair with one hand on the doorknob. Similarly, patients with limited literacy often conceal their lack of understanding to avoid shame (Parikh et al. 1996). Consequently, clinicians frequently fail to evaluate comprehension adequately and rarely take the time to teach their patients until they can confirm that critical self-management skills are understood (Schillinger et al. 2003). This approach is detrimental to patients. A standard of care that assumes a high level of literacy should be thought of as a risky venture.

We suggest a change in the standard of care — a “flipping” of the default — in which the universal assumption is limited literacy. The key added activity for the healthcare team would be to confirm comprehension of the clinical plan with every patient at multiple steps of the care continuum. This confirmation can be done with a “teach-back” model in which each patient is asked to state or exhibit the care plan so the healthcare team can provide additional education focused on items the patient has not understood until the patient is able to confirm comprehension (Schillinger et al. 2003). Ongoing education until a learner can confirm comprehension is known as a “teach-to-goal” or “teach-to-mastery” educational technique and has been shown to be effective (Paasche-Orlow et al. 2005a; Sudore et al. 2006a). For example, a study of confirming comprehension of the medication regimen and inhaler technique among patients with asthma revealed that: 1) patients with limited literacy had worse comprehension at baseline; 2) all patients were able to exhibit mastery after the teach-to-goal process; and 3) comprehension at 2 weeks was similar for patients with and without limited literacy (Paasche-Orlow et al. 2005a).

Available evidence suggests that confirming patient comprehension is worthwhile and would decrease the self-management deficits associated with limited literacy. Under current conventions, the amount of information given to patients seems to be linked to a clinician’s judgment of the complexity of the information, the severity of the risks, or other medicolegal attributes of healthcare. We want patient education to become a central priority of healthcare and think that it is appropriate to hold clinicians accountable for educating patients all the time, even for an illness as minor as the common cold.

Some may argue that this proposal is impractical due to the time and resources it would consume. Ultimately, ques-

tions about the strict utility of such investments in patient education are empirical questions of the cost-benefit analyses that would need to be evaluated in various settings. We hold that such cost-benefit analyses will need to be judged within the prioritarian framework we have laid out, i.e., that the cost of organizing healthcare teams to teach-to-goal will appropriately provide more benefit for the patients with the highest risk of worse health outcomes.

Furthermore, all learners have better comprehension and retention of information when presented with clear, succinct messages that are reiterated (Coyne et al. 2003; Flory and Emanuel 2004). While simple communication and confirming comprehension will help patients with limited literacy more than it will help patients without limited literacy, there is little downside in reorienting the system for limited literacy. Not only will patients’ self-management skills improve, but also, patients may learn that their providers really care about the specific tasks, which may promote adherence.

TECHNOLOGY-SUPPORTED COMMUNICATION

Our second proposal calls for developing and implementing communication technology models that promote meaningful communication and are successful for people with limited health literacy. The present healthcare system was designed by physicians who fashioned a medical system that works best for users who think, talk and act like physicians. The dominant iatroculture assumes the average healthcare user reads, writes, and thinks at a highly sophisticated level in which the spoken and written word are used to communicate complex medical and legal information.

The call for improved communication in medicine is hardly new. The medical literature is replete with studies showing the benefits of plain simplified language in the medical setting. This movement also calls attention to needed improvements in training healthcare providers in communication and patient education as well as the need to invest in a multilevel team approach to educate patients, especially in the context of chronic disease where improvement in outcomes is closely linked to self-management (Paasche-Orlow et al. 2006).

However, the complex ideas that users of the healthcare system must understand, such as advance care planning, medication regimens and medical decision-making, may not be optimally explained simply with verbal or written communication. These complex ideas can be facilitated by pictures, video, multimedia and other decision aids beyond the written and spoken word (Barry 2002; Woolf et al. 2005). We have successfully piloted a video to help patients with limited health literacy better envision and understand hypothetical health states such as dementia (Volandes et al. 2007). Other health information technologies, such as automated phone systems (Friedman et al. 1996; Migneault et al. 2006; Rubin et al. 2006), and automated computer interfaces such as animated embodied-conversational agents and “talking touch-screens” (Bickmore et al. 2005; Bickmore and Giorgino 2006; Hahn et al. 2004), are currently being

refined and tested in intervention studies for patients with limited health literacy.

Although there has been a slow rise in the number of articles promoting innovative media, there needs to be a concerted effort on the part of the healthcare system to invest and develop technologies that better promote meaningful communication. Care is needed, however, in how new communication technologies are implemented. Patients with limited health literacy may have limited access to newer technologies. While well designed and tested systems with simplified user interfaces have the potential to improve healthcare for people with limited health literacy, failure to ensure access to all and a lack of focus on how such systems will be used by people with limited health literacy could result in health information technologies that exacerbate inequalities in the healthcare system.

Some may argue that developing technology platforms to promote meaningful communication is too expensive in an already overly expensive healthcare system that is approaching 15% of the United States Gross Domestic Product. However, the rapidly decreasing price of digital technology and the increasing availability of web-based informational systems make the implementation and development of new technology feasible. Ideally, this technology should be tested for efficacy and cost/benefit, but there is reason to think that technology platforms may work as well as or surpass healthcare providers. Technology platforms are highly efficient and, unlike physicians, deliver what they are designed to deliver with high fidelity. Furthermore, such systems may be used to collect, store, and compare data, support self-management, as well as promote and facilitate communication between patients and their healthcare team. Considerations of the least well-off in the healthcare system will require creativity in alternative communication and patient education techniques that have been proven to be effective with patients who have limited health literacy. We are in a creative era of exploration in health information technology. Ultimately, while the risk of unequal access is real and the difficulty people have interacting with new technologies needs to be overcome, health information technologies provide a real opportunity to advance patient education for patients with limited health literacy.

A MORE JUST PAY-FOR-PERFORMANCE

Payors have begun to use healthcare process measures to influence physicians' reimbursement in programs loosely referred to as *pay-for-performance*. This trend should be reassessed through the perspectives of health literacy and the least well-off. Currently, such financial reimbursement schemes are "one size fits all" with respect to patient literacy and for the most part, patients with limited literacy are at a distinct disadvantage compared with high literacy patients through the lens of these various evaluative processes.

The typical pay-for-performance arrangement withholds partial compensation and then offers providers

bonuses for appropriately measuring specific laboratory tests (e.g., cholesterol test), conducting cancer screening (e.g., mammography), investing in electronic medical records and prescribing generic medications. For example, providers will get additional compensation per member per month if they meet or exceed the pre-set target for the percentage of patients with diabetes who have had a hemoglobin A1C (HbA_{1c}) test at least twice annually or the percentage of patients older than age 50 years who have undergone colorectal cancer screening (Rosenthal et al. 2005; Rosenthal and Frank 2006).

The goal is to improve quality. However, quality is defined in a manner that is driven by data that are easily derived from administrative databases, such as HbA_{1c} blood tests or colonoscopies. Patient education is not coded, so it cannot be promoted by current programs. Furthermore, patients who refuse a test are not removed from their clinician's score, i.e., clinicians must convince their patients to undergo colonoscopy. This design will lead clinicians away from patient education and toward marketing whatever targets are currently on the scorecard. Notwithstanding the ways this arrangement generally undercuts informed consent, patients with limited health literacy, who need more education and who are not as likely to use preventive services, will be seen more negatively as a result of pay-for-performance (Scott et al. 2002).

Some pay-for-performance plans categorize providers according to how well they adhere to the targets and link subscriber co-payments to the pay-for-performance tier of their primary care provider. In such a scenario, a provider might learn to view patients with limited health literacy as a professional liability that could cost all other patients higher co-pays as well as give the provider a worse reputation. Providers may attempt to evade penalty by avoiding patients who have lower rates of adherence to the pay-for-performance targets.

Current pay-for-performance programs have been shown to accrue financial benefit only to providers who do well on such measures prior to initiating the program (Rosenthal et al. 2005). To level the playing field for the least fortunate users of the healthcare system, we must be willing to invest disproportionately more resources on patients with limited literacy. To accomplish this, resources must be allocated specifically to healthcare settings that care for a disproportionate share of patients with limited literacy to hire diabetes educators, nutritionists, clinical pharmacologists, and other practitioners who are dedicated to patient education.

It is important to note that current programs that get providers to measure HbA_{1c} tests have not been shown to lead to improvement in the actual values of HbA_{1c} (O'Connor et al. 2005). This finding can be seen to show how some of the quality measures place an inordinate focus on the wrong kinds of behavior. A shift of quality measures away from items such as laboratory tests toward patient education may provide incentives to interact with patients in a way that will have a better chance of improving outcomes.

CONCLUSION

The empirical evidence is clear: limited health literacy negatively impacts health. We have presented three ways clinical care and health policy can be transformed to address the needs of patients with limited literacy. We hope that these ideas can be evaluated on their merits and that they might serve as a catalyst to introduce a broad discourse on unneeded complexity in the healthcare system. This is important because, in failing to meet the needs of patients with limited literacy, the healthcare system propagates a serious injustice. While the healthcare system may not rectify inequalities that transcend healthcare, such as inequalities in primary education, we should expect that the healthcare system not exacerbate underlying injustices. Unfortunately, this is precisely the impact of the current arrangement, as limited literacy has been shown to be an underlying mechanism of ethnic and racial health disparities (Saha 2006; Sentell and Halpin 2006).

Future attention and research focusing on the problem of unneeded complexity in healthcare may help ameliorate the clustering of disadvantage represented by those with limited health literacy, a population that is disproportionately elderly, non-white, less educated and chronically ill. As Powers and Faden (2006) point out, "inequalities are interactive," and to pursue the remedial task of aspiring for justice in the real world we need to identify through empirical methods how "inequalities of one kind beget inequalities of another kind" (8). The emerging literature on health literacy is providing such evidence. Not to focus attention on patients with limited literacy is to neglect a fundamental obligation of the healthcare system to its most vulnerable constituents.

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