

National Survey of Patients' Bill of Rights Statutes

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BACKGROUND: Despite vigorous national debate between 1999–2001 the federal patients' bill of rights (PBOR) was not enacted. However, states have enacted legislation and the Joint Commission defined an accreditation standard to present patients with their rights. Because such initiatives can be undermined by overly complex language, we surveyed the readability of hospital PBOR documents as well as texts mandated by state law.

METHODS: State Web sites and codes were searched to identify PBOR statutes for general patient populations. The rights addressed were compared with the 12 themes presented in the American Hospital Association's (AHA) PBOR text of 2002. In addition, we obtained PBOR texts from a sample of hospitals in each state. Readability was evaluated using Prose, a software program which reports an average of eight readability formulas.

RESULTS: Of 23 states with a PBOR statute for the general public, all establish a grievance policy, four protect a private right of action, and one stipulates fines for violations. These laws address an average of 7.4 of the 12 AHA themes. Nine states' statutes specify PBOR text for distribution to patients. These documents have an average readability of 15th grade (range, 11.6, New York, to 17.0, Minnesota). PBOR documents from 240 US hospitals have an average readability of 14th grade (range, 8.2 to 17.0).

CONCLUSIONS: While the average U.S. adult reads at an 8th grade reading level, an advanced college reading level is routinely required to read PBOR documents. Patients are not likely to learn about their rights from documents they cannot read.

KEY WORDS: patient rights; readability; policy; literacy.
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BACKGROUND

In 2001, both the U.S. House of Representatives and U.S. Senate passed bills to create a Federal Patients' Bill of Rights (PBOR). While the Senate version of the bill reversed certain elements of the Employee Retirement Income Security Act (ERISA), by allowing patients to sue in state and federal courts for denials of care by managed care organizations, the House version of the bill did not provide such a right and President Bush was reported to have threatened to veto the bill if it included such a provision.¹ The bill was moved to a House–Senate conference to work out differences between House-passed and Senate-passed bills, but these negotiations failed. Despite this, many states enacted Patients' Bill of Rights laws.^{2,3}

The concept of patients' rights represents a cultural shift that began to emerge 40 years ago when notions of informed consent and autonomy were first endorsed by court opinion and institutional policy.^{4,5} In 1973, the American Hospital Association

(AHA) presented the first patients' bill of rights.⁶ The 12 themes addressed in this initial document (e.g., right to respectful care, right to refuse treatment, right to confidentiality, right to refuse participation in research) have remained in subsequent versions (Table 1), and in the 1990s the Joint Commission phased in a requirement to inform every patient about their rights as a national standard for hospital accreditation (RI.2.20).

Unfortunately, efforts to advance patients' rights can be thwarted by inadequate attention to the complexity and language of the materials presented to patients. For example, while the average U.S. adult reads at an 8th grade reading level, informed consent documents and notices of privacy practices typically require the reading capacity of a high school graduate.^{7,8} We hypothesized that PBOR texts are also written at a level of complexity that far exceeds patients' average capacity. We therefore undertook a survey to determine the readability of PBOR texts in the United States. We included PBOR texts from a sample of U.S. hospitals and all PBOR texts designated by state law to be given to all patients. We performed the following three additional analyses of state PBOR statutes: 1) comparison of the rights delineated in state law to the themes advanced in the 2002 version of the American Hospital Association PBOR; 2) abstraction of any enforcement powers that are delineated within the statute; and 3) evaluation of the presence of PBOR texts in languages other than English for those states with mandatory language defined within the statute.

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Table 1. Frequency of American Hospital Association Patients' Bill of Rights Themes in State Statutes and Hospital Documents

Theme	State Statutes (N=23), %	Hospital Documents (N=240), %
The patient has the right to:		
1. Considerate and respectful care	78	97
2. Obtain current and understandable information	87	93
3. Refuse recommended treatment	87	97
4. Have an advanced directive	35	95
5. Privacy	87	93
6. Confidential communications and records	78	92
7. Review records	43	88
8. Indicated medical care including transfer to another facility	39	90
9. Be informed of business relationships that influence care	17	40
10. Refuse participation in research	74	58
11. Reasonable continuity of care	43	87
12. Be informed of charges as well as policies for patient responsibilities and resolution of conflicts	74	57

METHODS

Data Sources

We obtained state PBOR statutes by searching all 50 state government Web sites and legal codes in the Lexis-Nexus Data base. If this information was unclear, we contacted the legal counsel for the state Department of Public Health and Welfare and/or the legal counsel for the State Legislature. The focus of this analysis was PBOR material for general patient populations. As such, PBOR legislation intended for specific patient populations (e.g., psychiatric patients) or special circumstances (e.g., long-term care) were not included.

To obtain a sample of hospital PBOR documents, we used the U.S. News and World Report 2006 alphabetical state listing of the nation's "best hospitals"; in each state we searched the publicly available Web sites for every fourth general hospital on the list with the goal of obtaining 5 different PBOR documents from each state. We designated a document as different from other documents in the state sample if the language, excluding institutional names, was not exactly the same. In addition, documents had to be at least 300 words long to be included. This served to exclude documents that are merely advertisements or outlines of actual PBOR texts and ensured an adequate word count for readability analysis. In circumstances where multiple hospitals on the list had identical PBOR documents, we retained one copy of the PBOR and continued to search for additional documents. We continued to search the list until we found five unique documents of sufficient length per state or the list was exhausted by cycling through the list four times. All Web sites were accessed between July and August 2006.

Readability and Language Availability

Readability analyses were conducted on each hospital PBOR using three software programs; Prose: The Readability

Analyst, Grammatik 6.0, and Wstyle: Writing Style Analyzer (1992).⁹ For any state that designated the specific PBOR text to be presented to patients, the readability of such text was evaluated in the same fashion. In addition, for each state that designated the specific PBOR text to be presented to patients, we searched relevant Web sites for approved text in other languages.

Prose provides grade level estimates for eight readability formulas. The upper limit for most readability formulas is grade 17, which represents a 1st year graduate school reading level. Grammatik 6.0 software (1994) analyzes a text's sentence and vocabulary complexity. Wstyle categorizes writing style as Very Poor, Poor, Weak, Satisfactory, Good, Very Good, and Excellent.

Analysis of Themes

The specific rights that are protected in each state statute were abstracted and compared with the 12 themes in the 2002 version of the American Hospital Association PBOR. This process was conducted independently by two coders (MPO and DJ), who designated each AHA theme as present, present but altered, or not present. In addition, state PBOR themes not included in the AHA PBOR document were documented. Each instance of disagreement among reviewers was reevaluated in a joint conference for final classification until agreement was reached.

Protected Remedies

Any recourse delineated within the statute was abstracted. We also noted instances where the statute specifically limits a person's options to pursue legal remedies for breach of the rights delineated in the statute.

Statistical Analysis

We used the Wilcoxon signed-rank test to compare the average reading grade level of documents required by state statutes to the average reading grade level of the hospital sample in those states. The reading grade levels of PBOR documents of hospitals in states with a PBOR text defined by statute were compared to the reading grade levels for PBOR documents of hospitals in other states with use of the Wilcoxon rank sum test. All significance tests were two-tailed. Analyses were conducted with Stata version 8 (College Station, TX).

RESULTS

In two states, no relevant legislation was identified. In 25 states, PBOR laws existed exclusively for the protection of specific patient populations. Of the 23 states with PBOR legislation for general patient populations, nine states' laws presented a specific PBOR document for distribution to patients. We analyzed a total of 240 hospital PBOR documents from all 50 states; we did not find five unique hospital PBOR documents in Delaware (4), Hawaii (3), North Dakota (2), South Dakota (2) and Utah (4).

Table 2. Most Common Non-American Hospital Association Patients' Bill of Rights Themes in State Statutes and Hospital Documents

Non-AHA Themes	State Statutes (N=23), %	Hospital Documents (N=240), %
The patient has the right to:		
1. File a grievance	100	71
2. Examine and receive an explanation of the itemized bill regardless of source of payment	57	75
3. Respect for dignity and worth despite diagnosis	50	46
4. Visitation (and right to exclude visitors)	43	33
5. Prompt pain assessment, management, and relief	43	67
6. Have communication needs met (interpreter services, large print documents, etc.)	36	63
7. Exercise their rights without regard to sex, race, economic status, educational background, color, religion, ancestry, nation origin, sexual orientation or marital status, or the source of payment for care	29	67
8. Freedom from seclusion and restraint, unless clinically required or necessary to protect hospital staff	29	42
9. Receive care in a safe setting and help accessing protective services	21	58
10. Consideration of the ethical, cultural, spiritual, or psychosocial issues that arise in provision of care	14	33

Readability

The average reading grade level for the 240 hospital PBOR texts was 14.1 (95% confidence interval 13.9 to 14.3, range 8.2 to 17.0). The average reading grade level for each state's hospital sample of PBOR texts was 14.1 (95% confidence interval 13.8 to 14.4; range, 12.0, Maine, to 16.6, Minnesota). Nine states stipulated within their statute the actual PBOR text to be distributed to patients. The average reading grade level for these nine documents was 15.2 (95% confidence interval 13.8 to 16.7; range 11.6, New York, to 17, Minnesota) as seen in Table 3. Hospitals in these nine states rarely presented the text exactly as prescribed by state law (1 of 45). The reading grade level of hospital PBOR texts in these nine states was lower than the language specified by state law (14.7 vs. 15.2, p=0.14) and higher than the average reading grade level of hospital PBOR documents in other states (14.7 versus 14.0, p=0.05). Table 4 presents examples of excerpts from hospital PBOR texts for four common themes.

Text Presented in Other Languages in State Statutes

In six of the nine states that present statutory PBOR texts, the state presented the mandatory text exclusively in English; three of these states presented a PBOR document in Spanish and two of these states also presented documents in additional languages (New York: Italian, Russian, Greek, Chinese, Yiddish, and Creole; Minnesota: Hmong, Somali, Russian, and Laotian).

Specific Themes

Of the 12 AHA themes, state statutes included an average of 7.4 themes and hospital documents included an average of 9.8 themes. As seen in Table 1, the AHA theme that is least commonly presented is the right to be informed of business relationships that influence care. In the 23 state statutes and the 240 hospital documents there were 95 themes not addressed in the AHA document (e.g., pain management including opiates, receiving an itemized bill, and freedom from restraints). The most common non-AHA themes are presented in Table 2.

Table 3. Readability Statistics for Patients' Bill of Rights as Codified in State Law

State	Reading Grade Level ¹	Flesch Reading Ease ²	Sentence Complexity ³	Vocabulary Complexity ⁴	Writing Style ⁵
New York	11.6	52: Fairly difficult	25	55	Satisfactory
Pennsylvania	12.9	48: Difficult	43	56	Weak
California	15.0	35: Difficult	45	67	Weak
Florida	15.2	36: Difficult	75	50	Poor
Texas	16.1	27: Very difficult	50	66	Poor
New Jersey	16.3	29: Very difficult	55	66	Very poor
Massachusetts	16.5	18: Very difficult	70	55	Poor
New Hampshire	16.6	23: Very difficult	78	58	Poor
Minnesota	17.0	15: Very difficult	84	66	Poor
Average	15.3	31: Difficult	58	60	Poor

¹ **Reading Grade Level** is the average of eight readability formulas as calculated by **Prose: The Readability Analyst Software** (1988-1991)

² **Flesch Reading Ease** as calculated by **Prose: The Readability Analyst Software** (1988-1991).

³ **Sentence Complexity** (100 = most complex) as calculated by **Grammatik 6.0 Software** (1994). Score is based on the number of words and clauses in a document.

⁴ **Vocabulary Complexity** (100 = most complex) as calculated by **Grammatik 6.0 Software** (1994). Score is based on the number of syllables in a document and a comparison to a word list of unusual or difficult words.

⁵ **Writing Style** as calculated by **WStyle. Writing-Style Analyzer Software** (1992). Score is based on: 1) Active Voice—portion of sentences using only active verbs; 2) Word economy—ratio of words that convey meaning (verbs, nouns, adjectives, and adverbs) to supporting words (propositions, articles, etc.); 3) Readability—difference between the document's readability grade and the target-reader's grade; 4) Word choice—ratio of direct, active verbs and concrete nouns to abstract nouns and verbs transformed to nouns.

Table 4. Examples of Patients' Bill of Rights Text in Four Common Domains*

Readability Level	DOMAIN	
	Right to Refuse Care	Right to Privacy of Records
5th grade	<i>Tell us what medical care you want and what medical care you do not want.</i>	<i>We do not share your records unless you give us permission.</i>
8th grade	"Let you choose whether to accept or refuse treatments."	"Keep your hospital and medical records private."
12th grade	"You have the right to consent to or refuse treatment, as permitted by law, throughout your hospital stay. If you refuse a recommended treatment, you will receive other needed and available care."	"You have the right to expect that treatment records are confidential unless you have given permission to release information or reporting is required or permitted by law. When the hospital releases records to others, such as insurers, it emphasizes that the records are confidential."
16th grade	"The patient has the right to make decisions about the plan of care prior to and during the course of treatment and refuse a recommended treatment or plan of care to the extent permitted by law and hospital policy and to be informed of the medical consequences of this action. In case of such refusal, the patient is entitled to other appropriate care and services that the hospital provides or be transferred to another hospital. The hospital should notify patients of any policy that might affect patient choice within the institution."	"The patient has the right to expect that all communications and records pertaining to his/her care will be treated as confidential by the hospital, excepting cases such as suspected abuse and public health hazards when reporting is permitted or required by law. The patient has the right to expect that the hospital will emphasize the confidentiality of this information when it releases it to any other parties entitled to review information in these records."
	Right to Know Names of Providers	Right to See Bill
5th grade	<i>The doctors and nurses must tell you their names.</i>	<i>You have the right to see your bill.</i>
8 th grade	"Tell you the names and roles of the people caring for you."	"Show you your bill and explain it to you, no matter how it is paid."
12th grade	"Be informed of the name and position of the doctor who will be in charge of your care in the hospital."	"You have the right to an examination and explanation of your bill, regardless of how it is paid."
16th grade	"Upon request, to obtain from the facility in charge of his care the name and specialty, if any, of the physician or other person responsible for his care or the coordination of his care."	"Every such patient or resident of said facility in which billing for service is applicable to such patient or resident, upon reasonable request, shall receive from a person designated by the facility an itemized bill reflecting laboratory charges, pharmaceutical charges, and third party credits and shall be allowed to examine an explanation of said bill regardless of the source of payment. This information shall also be made available to the patient's attending physician."

* Quotations denote verbatim excerpts from hospital documents. The readability level represents the overall reading level of the document from which the excerpt was taken. Text that is not in quotations and presented in italics was written by the authors

Recourse

Each state's statute established an internal and external grievance policy. In most of these states, complaints may be directed to the State Department of Health and in several states complaints are directed to the board of registration. For example, in Vermont complaints are directed to the board of medicine and failure to comply with any provision of the Patients' Bill of Rights law may constitute a basis for disciplinary action against a physician. In one state, Illinois, the law stipulated fines for violations and in four states (Arizona, Massachusetts, Maine, and Texas), the statute protects a private civil right of action. For example, under Texas law "A plaintiff who prevails in a suit under this section may recover actual damages, including damages for mental anguish even if an injury other than mental anguish is not shown."¹⁰ In contrast, the Florida statute included language to explicitly restrict patients' legal options: "This section shall not be used for any purpose in any civil or administrative action and neither expands nor limits any rights or remedies provided under any other law."¹¹

DISCUSSION

Our findings suggest that PBOR documents presented in U.S. hospitals far exceed the reading capacity of the majority of

adults. In addition, these documents commonly fail to include themes designated by state law and by the American Hospital Association. While close to half of the states in the U.S. have Patients' Bill of Rights legislation for the general public, the specific rights named in these laws vary and few of these laws incorporate remedies other than a mechanism to file complaints. Furthermore, in nine states statutory language to be presented to patients is very complex and is usually exclusively presented in English.

These observations may not be surprising for people who know that other documents such as informed consent forms and notices of privacy protection have also been shown to be overly complex. Efforts to empower patients are undermined by legal jargon in many instances. Similarly, efforts to cultivate communication skills and inculcate the importance of patient education in trainees are hampered by the mixed message presented by patients' rights documents that patients cannot read. Students may be taught that they should care about health literacy and low English proficiency while simultaneously observing what may appear as institutional indifference in the domain of patients' rights documents.

There are several reasons why clinicians and other patient advocates should particularly care about the readability and language accessibility of PBOR documents. Patients' Bill of Rights documents are publicly presented. They are among the initial points of patient engagement. Complex public documents may serve to train patients to be more passive in their care and

may instill fear in patients with limited literacy or English proficiency. Many clinicians probably view the PBOR as a health system issue that does not directly impact clinical practice or their relationships with patients. However, a well-presented PBOR document has the capacity to encourage patient activation and trust in those providing services. The current research, which demonstrates that PBOR documents are frequently not understandable to patients, reveals a missed opportunity to present the patient care mission in a clear manner.

In the 1970s, the patients' rights movement was advanced because physicians were perceived as too powerful.¹² At that time, patients had to advocate for the right to be given information about their diagnosis and prognosis.¹³ By the 1990s, when the concept of a patients' bill of rights was introduced in Congress, the topic was advanced by a consumer rights movement due to a sense that managed care companies and insurers were too powerful.¹⁴ Instead of protecting a right to refuse treatment from paternalist physicians, consumers wanted to secure a right to choose their providers and have access to treatments being denied by payors.

The American Hospital Association, which has long been an advocate for a patients' bill of rights, changed their format in 2006 to a brochure called "The Patient Care Partnership," which contains the same themes and "informs patients about what they should expect during their hospital stay with regard to their rights."¹⁵ While the brochure is a clear departure from the legal jargon of prior PBOR documents advanced by the American Hospital Association (and is presented on their Web site in Arabic, Chinese, English, Russian, Spanish, Tagalog, and Vietnamese), the English text is still written at an 11th grade reading level.

As seen in Table 4, where we present examples written at a 5th grade level, the themes of the PBOR can be written in plain English. In most states, hospitals are free to revise their PBOR documents; however, in nine states (CA, FL, MA, MN, NH, NJ, NY, PA and TX) statutes should be amended either to allow hospitals to write their own language or to present the official state PBOR in plain English. A note of caution is warranted. According to Robert Gunning, developer of the Fog readability formula: "Like all good inventions, readability yardsticks can cause harm in misuse. They are handy statistical tools to measure complexity in prose...*But they are not formulas for writing.*"¹⁶ Authors who replace long words with short words that are similarly arcane have not improved the actual readability, even if they do reduce their readability score.^{17,18}

Different formulas report grade levels that vary by two to four grades, partly because they are based on different levels of reader comprehension. Because the SMOG formula is based on 100% reader comprehension, it tends to score higher than other formulas which are based on 35%–70% reader comprehension. Rather than using a single formula that might bias the results by scoring "high" or "low," we used Prose software because it provides the average grade level estimates of eight readability formulas. In addition, we provide further analyses to exhibit the level of complexity of the PBOR documents.

There are limitations to readability software programs. First, the same formula in different programs may give different grade levels due to variations in algorithms used to count sentences and syllables.¹⁷ Second, formulas do not take into account a PBOR's organization, font size, font family, etc. Third, these formulas cannot account for the background knowledge of the readers, their motivation, cultural experi-

ences, etc. Despite these limitations, the formulas do provide a reasonable and cost-effective way of assessing how clearly PBORs are written.

Interested hospitals and legislatures may benefit from consulting specialists in adult basic education, readability, and improving patient care systems in this process. Patients and their advocates can also play an important role. In addition, plain language versions in other languages should be commissioned. Similarly, hospitals can improve patients' comprehension of their rights by supplementing their print material with other educational methods such as video or interactive multimedia that can be developed. A promising proposal for a National Health Literacy Act, to establish a national center for health literacy at the Agency for Healthcare Research and Quality as well as provide funding for State Health Literacy offices, is currently being vetted.¹⁹ Resources of this kind could help avoid future instances of legislatures compelling hospitals to present unreadable legal jargon to patients.

The strengths of this study that lend weight to our conclusions are the amount of text analyzed, the blind sampling within every state, and the complete evaluation of state statutes. Nonetheless, several limitations should be kept in mind. First, we surveyed only hospital PBOR texts that were available through institutional Web sites. Although it is likely that the materials presented on institutional Web sites accurately reflect local practices, additional materials were not examined. Second, we did not attempt to evaluate the conceptual complexity of the content. It is possible that variations in conceptual complexity influence readability as well. Third, we evaluated readability using the average of eight readability formulas and three measures of syntax and semantics: sentence complexity, vocabulary complexity, and writing style. While this represents a significant advance over the vast majority of published analyses which are based simply on the Flesch-Kincaid scale, or other single metrics of readability, additional factors that affect legibility and understandability, such as the type font, layout, and length, were not evaluated in this project. Similarly, we were not able to evaluate the readability of PBOR documents in languages other than English to determine, for example, if the Minnesota State PBOR, which is at a graduate school level in English, is also at a 17th grade level in Hmong, Somali, Russian and Laotian. Fourth, we report the remedies offered within statutes; however, this does not reflect the volume or types of complaints that these statutes have actually generated. We made multiple attempts to determine details of these programs, but were not able to obtain records on complaints or otherwise assess the consequences of PBOR statutes. It would be valuable to know how patients and states use these programs.²⁰

When a hospital PBOR document is missing a theme that is recommended by the AHA or required by state statute, it is unclear if this represents an accidental lapse or a purposeful departure. The absence of themes from PBOR documents, however, does not change clinical standards. For example, the least common AHA PBOR theme presented in hospital documents and state statutes relates to the disclosure of business relationships that may influence care. Nonetheless, professional standards dictate disclosure of such relationships.²¹

Promoting patients' rights has had many years of regulatory support from the AHA and the Joint Commission. Similarly, almost half the states in our country have shown legislative support for a bill of rights to protect all patients. These laws do

not establish a right to health care. Yet, patients' rights statutes are designed to promote the ethical and humane treatment of patients. These goals will not be realized by presenting patients with documents they are not able to read and understand.

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