

Steven Walfish and Sean P. Sharp, "Readability Level of HIPAA Notices of Privacy Practices Used by Physical Rehabilitation Centers," *The Journal of Clinical Ethics* 16, no. 2 (Summer 2005): 156-9.

Readability Level of HIPAA Notices of Privacy Practices Used by Physical Rehabilitation Centers

Steven Walfish and Sean P. Sharp

Steven Walfish, PhD, is a Visiting Lecturer in the Department of Psychology at Georgia State University in Atlanta, and is a Psychologist at the Atlanta Center for Cognitive Therapy, *psych_pubs@aol.com*.

Sean P. Sharp is a BS Candidate in the Department of Psychology at Kennesaw State University in Kennesaw, Georgia. © 2005 by *The Journal of Clinical Ethics*. All rights reserved.

Physiatrists (physicians who specialize in physical medicine and rehabilitation) have an ethical obligation to assure that their patients understand the documents that they sign to assent to treatment. Section 8.08 of the American Medical Association (AMA) *Code of Medical Ethics* addresses this issue directly: "The patient's right of self-decision can be effectively exercised only if the patient possesses enough information to enable an intelligent choice."¹ This may present a problem to the developers of informed-consent documents; 50 percent of the adult population read at or below a ninth-grade reading level.² In 2003, Paasche-Orlow and colleagues reported in the *New England Journal of Medicine* that most informed-consent documents were written at a grade level higher than would be understandable to the average American adult.³

In April 2003, the federal government implemented the Health Insurance Portability and Accountability Act (HIPAA), which mandates the adoption of privacy protections for individuals' health information.⁴ Healthcare providers are required to provide patients with a Notice of Privacy Practices (NPP), a form that explains how providers may use their patients' personal medical information and the patients' rights under HIPAA. Patients are asked to sign, initial, or otherwise acknowledge that they receive this notice. It is similar to signing an informed-consent document, acknowledging and agreeing to accept treatment or to participate in research.

As an extension of previous research on readability of informed-consent documents,⁵ the current investigation examines the readability of NPPs that were obtained from physical rehabilitation centers around the United States.

METHOD

PROCEDURE

NPPs were gathered from independent rehabilitation centers or rehabilitation units within hospitals from each of the 50 states and Washington, D.C. All of the forms were acquired via the internet in July 2003. The documents were rated for ease of reading and comprehension using the Flesch formulas,⁶ which are included

with Microsoft Word (MSWord).⁷ The Flesch Reading Ease formula examines the average length of sentences in a text and the average number of syllables per word to assign the text a number from 0 to 100; a higher score indicates easier reading. MSWord suggests that an easy-to-read document should score within the 60 to 70 point range. A score of below 30 falls into the "very difficult" range. The Flesch-Kincaid Grade Level formula converts a document's Flesch Reading Ease score to a grade-school level; that is, a document with a score of 7.0 would indicate that a seventh-grade student should be able to understand the text. MSWord suggests that a document should have a Flesch-Kincaid score between 7.0 and 8.0; the ceiling for this measure is 12.0.

RESULTS

The reading grade levels and reading ease scores of the NPPs surveyed are presented in table 1. Of the 51 NPPs analyzed, the mean grade level was 11.47. The NPPs of only three states (5.9 percent) fell below the tenth grade level; the two lowest scores had a grade level score of 8.6. The highest grade-level score of 12.0 was achieved by 35 (68.6 percent) of the NPPs surveyed.

The average reading ease score was 37.83 (standard deviation, or S.D., = 8.22). The lowest score was an 18.8. None of the samples yielded a score within the optimal 60 to 70 range. NPPs from three of the states

Table 1
Readability Levels of NPPs of Rehabilitation Centers

State	Flesch-Kincaid Grade Level Score	Flesch Reading Ease Score	State	Flesch-Kincaid Grade Level Score	Flesch Reading Ease Score
Alabama	12.0	40.0	Nebraska	12.0	42.1
Alaska	12.0	30.5	Nevada	12.0	40.2
Arizona	12.0	36.9	New Hampshire	12.0	33.7
Arkansas	12.0	37.4	New Jersey	12.0	34.9
California	8.6	46.7	New Mexico	11.6	41.6
Colorado	12.0	38.4	New York	11.7	44.0
Connecticut	12.0	38.2	North Carolina	12.0	41.2
Delaware	11.6	43.1	North Dakota	11.6	41.9
Florida	12.0	39.1	Ohio	12.0	42.1
Georgia	11.4	48.0	Oklahoma	12.0	40.1
Hawaii	9.6	42.7	Oregon	11.8	43.7
Idaho	12.0	40.1	Pennsylvania	12.0	37.8
Illinois	12.0	35.2	Rhode Island	12.0	39.0
Indiana	12.0	34.6	South Carolina	8.6	50.0
Iowa	12.0	27.3	South Dakota	11.5	42.0
Kansas	12.0	28.9	Tennessee	11.5	41.9
Kentucky	12.0	32.8	Texas	12.0	18.8
Louisiana	12.0	39.8	Utah	12.0	34.7
Maine	12.0	33.9	Vermont	11.6	34.9
Maryland	12.0	39.8	Virginia	12.0	31.2
Massachusetts	12.0	39.9	Washington	11.0	49.3
Michigan	11.3	45.8	Washington, D.C.	12.0	42.7
Minnesota	10.6	48.4	West Virginia	12.0	38.6
Mississippi	12.0	39.6	Wisconsin	10.6	48.4
Missouri	12.0	42.7	Wyoming	12.0	31.6
Montana	12.0	33.6			

(5.9 percent) scored below 30, in the "very difficult" range. The vast majority (94 percent) fell in the "difficult" range of reading ease.

DISCUSSION

Careproviders have an ethical obligation to assure that patients understand the documents that they are asked to sign to participate in medical treatment or research. In addition to the *AMA Code of Medical Ethics* noted above, the issue of readability is also addressed in the ethical codes of rehabilitation counselors and psychologists, two groups of careproviders who are actively involved as members of treatment teams in rehabilitation centers. The *Code of Ethics for Rehabilitation Counselors* states:

Rehabilitation counselors shall respect the integrity and protect the welfare of people and groups with whom they work. The primary obligation of rehabilitation counselors is to their clients. . . . Rehabilitation counselors shall serve as advocates for their clients and people with disabilities. . . . Rehabilitation counselors will take steps to ensure that clients understand the implications of diagnosis, the intended use of tests and reports. . . . Clients have the right to expect confidentiality and will be provided with an explanation of its limitations, including disclosures to supervisors and/or treatment team professionals. . . . Rehabilitation counselors will explain the nature and purposes of assessment and the specific use of results in language the client can understand.⁸

Section 3.10 of *The Ethical Principles of Psychologists and Code of Conduct of Psychologists* reads as follows: "When psychologists conduct research or provide assessment, therapy, counseling, or consulting services in person or via electronic transmission or other forms of communication, they obtain the informed consent of the individual or individuals using language that is reasonably understandable to that person."⁹ Since 50 percent of the adult population reads below a ninth grade level,¹⁰ the results of the present investigation suggest that each time a patient at a rehabilitation center is provided with an NPP (which occurs on a daily basis) there is a significant risk of a violation of one (or more) of the ethical codes cited above.

The majority of the NPPs surveyed in this study reached the Flesch-Kincaid Grade Level ceiling of 12.0, which indicates that these informed-consent documents are written at the college level. The mean readability grade level is a low estimate, because this readability measure has a twelfth grade ceiling. The mean grade level for the NPPs surveyed would probably have scored higher using a readability scale that had a higher ceiling.¹¹ Further, all of the NPPs surveyed fell into the "very difficult" or "difficult" range of reading ease.

It has been suggested that a good informed-consent process leads to better outcomes and avoids potential risks.¹² What is clear is that NPPs do not have to be written at a difficult reading level. In an investigation of informed consent to participate in medical research, it was found that these documents could be written at an eighth grade level or below.¹³ In a consultation to a specialty medical clinic, the senior author of this article was able to reduce the reading level and increase the reading ease of an NPP without changing its content. Before the consultation with the author, the NPP had a Flesch-Kincaid Grade Level score of 12.0; after the consultation, the grade level score was reduced to 7.2. Similarly, the Flesch Reading Ease score of the original document was 40.7 (in the "difficult" range); after the consultation, this was increased to a score of 66.8 (in the "optimal" range). With an understanding of what makes a document readable, rehabilitation centers may rework their NPPs. In this way, they do not have to risk making repetitive ethical violations, can reduce their liability, and can improve their informed-consent process, which Handelsman suggests could lead to better treatment outcomes.¹⁴

It is unclear how the NPPs examined in the current investigation were developed. Some may have been written by the rehabilitation centers themselves. More likely they were purchased from a professional organization or private company that emerged to assist facilities to comply with HIPAA requirements. However, it should be pointed out that the burden of ethical practice falls on rehabilitation centers that utilize these documents in their work with patients. For this reason, all rehabilitation centers should consider revising their NPPs to a level that is readable by the majority of their patients.

ACKNOWLEDGMENTS

This work was completed while the first author was affiliated with the Department of Psychology at Kennesaw State University. The authors thank Randy Smith, PhD, and the Department of Psychology for their support of this work.

NOTES

1. American Medical Association, Council of Ethical and Judicial Affairs, *Code of Medical Ethics* (Chicago, Ill.: AMA, 2002).
2. C. Doak, L. Doak, and J. Root, *Teaching Patients with Low Literacy Skills* (Philadelphia, Pa.: Lippincott, 1996).
3. M. Paasche-Orlow, H. Taylor, and F. Brancati, "Readability Standards for Informed Consent Forms as Compared with Actual Readability," *New England Journal of Medicine* 348 (2003): 721-6.
4. U.S. Department of Health and Human Services, *Fact sheet: Protecting the Privacy of Patients' Health Information*, www.hhs.gov/news/facts/privacy.html, accessed 26 July 2003.
5. See note 1 above.
6. R. Flesch, *The Art of Readable Writing* (New York: Collier Books, 1949).
7. Microsoft Office Word 2003.
8. Commission on Rehabilitation Counselor Certification, *Code of Professional Ethics for Rehabilitation Counselors* (2003), http://www.crc certification.com/pdf/code_ethics_2002.pdf, accessed 26 July 2003.
9. American Psychological Association (2002). *The Ethical Principles of Psychologists and Code of Conduct* (2002), <http://www2.apa.org/ethics/code2002.doc>, 26 July 2003.
10. See note 2 above.
11. E. Fry, "Fry's Readability Graph: Clarifications, Validity and Extension to Level 17," *Journal of Reading* 21 (1977): 242-52.
12. M. Handelsman, "Accurate and Effective Informed Consent," in *The Mental Health Desk Reference*, ed. E.R. Welfel and R.E. Ingersoll (New York: Wiley, 2001), 453-8.
13. See note 3 above.
14. See note 12 above.