

The Medical Library Association Guide to Health Literacy

Marge Kars
Lynda M. Baker
Feleta L. Wilson

EDITORS

Neal-Schuman Publishers, Inc.
New York London

Published by Neal-Schuman Publishers, Inc.
100 William St., Suite 2004
New York, NY 10038

Copyright © 2008 by the Medical Library Association.

All rights reserved. Reproduction of this book, in whole or in part, without written permission of the publisher, is prohibited.

Printed and bound in the United States of America.

The paper used in this publication meets the minimum requirements of American National Standard for Information Sciences-Permanence of Paper for Printed Library Materials, ANSI Z39.48-1992.

Library of Congress Cataloging-in-Publication Data

The Medical Library Association guide to health literacy / Marge Kars, Lynda M. Baker, Feleta L. Wilson, editors.

p. cm.

Includes bibliographical references and index.

ISBN 978-1-55570-625-8 (alk. paper)

1. Medical librarianship—United States—Handbooks, manuals, etc. 2. Health education—United States—Handbooks, manuals, etc. 3. Patient education—United States—Handbooks, manuals, etc. 4. Literacy—United States—Health aspects. 5. Social medicine—United States. 6. Medical libraries—Reference services—United States. 7. Libraries and illiterate persons. 8. Libraries and people with social disabilities. 9. Libraries and community. 10. Communication in medicine. I. Kars, Marge, 1947- II. Baker, Lynda. III. Wilson, Feleta, 1945-

Z675.M4M497 2008
026'.610973—dc22

2008023323

Contents

List of Figures, Tables, and Appendices	ix
Preface	xi

Part I. Health Literacy: Understanding the Issues

Chapter 1. Introduction to Health Literacy	3
<i>Lynda M. Baker, Marge Kars, and Feleta L. Wilson</i>	
Chapter 2. Review of the Literature	9
<i>Nancy Schaefer</i>	
Definitions of Health Literacy	9
Components of Health Literacy	11
Special Health Literacy	12
Characteristics Correlating to Low Health Literacy	13
Reasons for Concern	14
Consequences of Low Health Literacy	19
Proposed Solutions	20
References	28
Chapter 3. Social Practices in Talk as Components of Health Literacy	55
<i>Charlene Pope</i>	
Introduction	55
The Expanding Definition	56
Theories of Language and Their Contribution to Health Literacy	58
Social Practice in the New Forms of Health Literacy	59
Social Biases and Their Role in Social Practice and Health Literacy	60
Bridges to a More Multidimensional Health Literacy Solution	61
Solutions	63
References	64

**Part II. Health Literacy Issues in Special Populations:
The Influence of Culture, Ethnicity, Special Needs,
and Age on Health**

Chapter 4. Cultural Competence and Health Literacy	73
<i>Misa Mi</i>	
Introduction	73
Culture and Health	74
Cultural Competence for Healthcare Providers	75
Barriers to Cultural Competence	76
Models for Cultural Competence	77
Cultural Competence for Librarians	78
Cultural Competence Training	80
Importance of Culture in Understanding Health Literacy	80
Promoting Health Literacy	81
Challenges and Opportunities for Improving Health Literacy	83
Summary	86
References	86
 Chapter 5. Impact of Patient Low Literacy on the Individual and Family	 93
<i>Feleta L. Wilson</i>	
The Impact of Low Literacy on the Patient	94
Individuals with Low Literacy Skills: Who Are They?	95
Family Health Literacy	96
Health Disparities Associated with Low Literacy Patients	98
Partnerships Between Nurses and Librarians	99
References	100
 Chapter 6. The Association Between Literacy and Health: Providing Health Information to Adults with Low Literacy	 103
<i>Heather J. Martin and C. Nadine Wathen</i>	
Introduction	103
What Is Health Literacy and Why Is It Important?	105
Low Literacy and Poor Health	106
Methods of Delivering Health Information to Individuals with Low Literacy	108
A Role for Librarians	110
Conclusion	112
References	113

Chapter 7. Health Literacy for People with Disabilities	117
<i>Shelley Hourston</i>	
Importance of Health Literacy Skills for People with Disabilities	117
Major Issues Affecting Health Literacy Skills for People with Disabilities	121
Reflections from Consumers	123
The Role of Librarians in Health Literacy for People with Disabilities	132
Direction for the Future	136
References	136
Chapter 8. Health Literacy and America’s Senior Citizens	139
<i>Marcy Brown</i>	
Review of Existing Research	140
A New Model of Health Literacy	143
Health Literacy Interventions Outside the Library	145
Librarians and Health Literacy Interventions	148
Learning Strategies for Older Adults	153
Future Directions for Libraries and Librarians	156
References	158
Chapter 9. A New Digital Divide: Teens and Internet Literacy	161
<i>Ellen Freda, Jonathan Hayes Goff, and Andrea L. Kenyon</i>	
Introduction	161
Background	161
Summer Teen Editor Program Goals	163
Program Methods	163
Program Materials and Expenses	164
Overview of Program Sessions	164
Summary of Program Findings	166
What Worked	168
What Did Not Work	169
Lessons Learned	171
Our Cautionary Tale: A New “Digital Divide”	171
Conclusion	172
References	174

**Part III. Health Literacy Issues in Public and Hospital Libraries:
Providing Programs and Services to Help Consumers Understand
Their Healthcare**

Chapter 10. The Health Reference Interview: Getting to the Heart of the Question While Assessing Your Customer's Literacy Skills	181
<i>Karyn Prechtel</i>	
The Health Reference Interview	183
Be Aware of the Person Asking the Question	184
Get as Much Information as Possible	184
Ask If They Have a Deadline	185
Is the Question Still Not Clear?	185
Follow-up	187
What Not to Do	188
What You Should Do	190
Reference Interview and Literacy Levels	190
Challenges of Telephone and E-mail Queries	191
Conclusion	195
References	195
 Chapter 11. Public Libraries and Health Literacy	 197
<i>Barbara Bibel</i>	
Community Assessment	198
Collection Development	199
Training	200
Collaboration and Partnership	201
Outreach	202
Conclusion	204
References	204
 Chapter 12. Health Literacy in Canada: Highlighting Library Initiatives	 209
<i>Susan Murray</i>	
Canadian Library Scene	211
British Columbia	211
Nova Scotia	212
Ontario	213
Quebec	214
Conclusion	215
References	215

Chapter 13. Consumer Health Services in Hospitals: The Front Line for Health Literacy	217
<i>Julie Esparza</i>	
Consumer Health Services in Hospital Libraries Survey (CHSHL)	218
Internal Partnerships	218
Availability of Collection	221
Packets of Information	225
Outreach Services	231
Partnerships and Services	235
Conclusion	238
References	238
Chapter 14. Health Literacy in Action—The Bronson Experience	243
<i>Marge Kars</i>	
Literature Review	243
The Bronson Initiatives	245
Other Bronson Health Literacy Initiatives	247
The Health Sciences Library Initiative	248
The Nursing Initiative	249
Lessons Learned	250
References	250
Part IV. The Future: Ways to Initiate and Become Involved with Health Literacy Programs	
Chapter 15. Intervention Programs for Health Literacy	259
<i>Cleo Pappas</i>	
What Is an Intervention?	259
Poor Health Literacy	260
Do Reading Levels Correspond to Consumer Needs?	261
Consequences of Poor Health Literacy	262
The Role of JCAHO	262
Institutional Review Boards (IRBs) and Informed Consent	263
Role of Librarians	266
Role of Pharmacists	268
Readability	269
Conclusion	271
References	271

Chapter 16. Forming and Funding Collaborations to Address Health Literacy	281
<i>Kristine Alpi and Dina Sherman</i>	
Identifying Existing Health Literacy Collaborations	282
Local Example: New York Health Literacy Collaborations	286
Identifying Funding for Collaborative Efforts	291
Working Successfully with Funding Agencies	293
Sustaining Collaborations in Health Literacy	294
Conclusion	294
References	294
About the Editors and Contributors	299
Index	305

List of Figures, Tables, and Appendices

FIGURES

Figure 10-1	Online Form for E-Mail Queries	193
-------------	--------------------------------	-----

TABLES

Table 13-1	Library and Internal Hospital Consumers	219
Table 13-2	Availability of Collection to the Public	222
Table 13-3	Packets of Information for Customers	226
Table 13-4	Outreach Services	231

APPENDIXES

Appendix 2-1	Readability Formulae	45
Appendix 2-2	Literacy Tests Used in Healthcare Settings	46
Appendix 4-1	Cultural Competence Course	91
Appendix 4-2	Course Module Sequence	92
Appendix 9-1	Initial Survey Form	175
Appendix 9-2	Initial Survey Results	176
Appendix 9-3	Final Evaluation Form	176
Appendix 9-4	Final Evaluation Results—Web Site Features	178
Appendix 9-5	Final Evaluation Results—Internet Experience Preferences	178
Appendix 11-1	A Quick Guide to Searching for Census Information	206
Appendix 11-2	Sources for Foreign Materials	207
Appendix 13-1	Consumer Health Services in Hospital Libraries Survey	241

Appendix 14-1	Original Version of the Bronson Hospital Release Assignment Form	252
Appendix 14-2	Revised Version of the Bronson Hospital Release Assignment Form	254
Appendix 15-1	Resources on Health Literacy for Librarians	274
Appendix 16-1	METRO Special Interest Group on Consumer Health One-Day Conference on Health Literacy: Preconference Survey	297

Preface

Health literacy is a vital component of consumer health. The publication of the Institute of Medicine's report *Health Literacy: A Prescription to End Confusion* (2004), coupled with the 2003 *National Assessment of Adult Literacy* (NAAL), brought national attention to a serious problem: people with low literacy skills often cannot read or understand information about their diagnosis, medications, or appointments with their physician. They may be unable to understand the directions for preparing for a medical test, or use written information about staying healthy. These same individuals have a higher incidence of disease, risk higher use of the emergency room, have longer hospital stays with higher hospital admission rates, and suffer medication errors because they cannot read or understand a prescription label. Librarians in all types of libraries can play a major role in health literacy, helping consumers to access and better understand health information.

The idea for *The Medical Library Association Guide to Health Literacy* evolved from my own experience working in a hospital-based consumer health library providing health information to consumers, and from discussions with colleagues who work with customers, in all types of libraries, looking for understandable health information.

The Medical Library Association, the world's preeminent educational organization for health information professionals, recognizing the important role that librarians play in providing health information, has partnered with other library organizations, on the state and national levels, to increase awareness of the seriousness of this issue and collaborate to create solutions for healthcare consumers.

In 2006, I invited two colleagues from Wayne State University, Detroit, Michigan—Lynda M. Baker (Library and Information Science Program) and Feleta L. Wilson (College of Nursing)—to work with me on this book about health literacy. Lynda and Feleta were the first to publish in LIS journals studies

of the literacy levels of consumer health materials. Because the importance of health literacy transcends any particular library boundary, we decided the book should be a forum for LIS professionals involved in the health literacy movement. To provide a comprehensive overview, we recruited practitioners from all types of libraries, as well as researchers in academia, to write about health literacy from their unique perspectives. After reading this guide, librarians should be better able to understand the issues that comprise health literacy, learning how to help others become health literate and how to become change agents within their organizations.

As editors, we have tried to ensure the use of gender-neutral language throughout the book. Because we find “he/she” to be clunky, we have chosen to use either “she” or “he” as equally as possible. This book is not meant to be read from cover to cover; rather, we believe readers will select chapters relevant to their situations and interests. Therefore, instead of having one definition of health literacy located in the Preface, we have allowed authors to define health literacy as it relates to and forms the basis of their work.

The Medical Library Association Guide to Health Literacy features 16 chapters, divided into four parts. The four parts:

- cover the essential issues surrounding health literacy;
- identify often overlooked implications of the influence of culture, ethnicity, special needs, and age in health;
- highlight the nation’s best practices for public and hospital library consumer health programs and services; and,
- suggest proven ways libraries can initiate their own and partner with other organizations’ health literacy programs.

In Chapter 1 the editors provide an introduction to the issues of health literacy. The different types of health literacy are defined in Chapter 2, along with a discussion on causes, effects, and solutions. A comprehensive list of readability formulae and literacy tests used in the healthcare setting is included with this chapter.

Chapter 3 looks at the role social bias plays in health encounters and how it affects health literacy. The author discusses theories of language and their contribution to health literacy, the health encounter as a literacy event, and social biases in relation to health literacy and their effects on provider and patient behavior and institutional practices. Health literacy within the context of culture, as well as the importance of cultural competency of librarians in relation to a client’s health literacy skills is the subject of Chapter 4. An outline and sequence of activities for a course titled “Cultural Competence for Health Information Professionals,” developed by the author, is presented in this chapter.

Chapter 5 covers the impact of low literacy on the patient and the family from a nursing perspective. The author discusses characteristics of patients with low literacy, the association between low literacy and health disparities, and the need for partnership between nurses and librarians. This disturbing divide is further explored in Chapter 6, which summarizes the literature on the relationship between low literacy levels and the effects on patient care and health outcomes. The authors also discuss the role librarians can take in helping to narrow the health literacy gap.

Raising awareness of the complexities of health literacy for people with disabilities is the focus of Chapter 7. The author addresses how librarians can partner with people with disabilities and the community. She includes some personal perspectives of people with various types of disabilities about health literacy and ways libraries and librarians can help them find information.

Chapter 8 posits a new model of health literacy. The author looks at health literacy within the context of senior citizens, provides some examples of health literacy interventions both inside and outside the library. Chapter 9 describes the authors' efforts to build a foundation of health literacy among adolescents in Philadelphia. Useful information on what worked and what does not work in their collaboration with the teens is also presented.

The health reference interview is part of the individual's ability to obtain or access health information. This initial step in the health literacy process is the focus of Chapter 10.

Public libraries should be the major provider of consumer health information. Chapter 11 features a particularly successful collaboration between a public library and a hospital library. The author also provides a list of sources of non-English language materials for a library's collection.

Some of the health literacy initiatives by Canadian librarians and the difficulties in finding information on the activities of librarians in the area of health literacy are addressed in Chapter 12.

The results of a study on consumer health services provided by hospital librarians are provided in Chapter 13; this chapter also highlights what other hospital libraries have done to address health literacy. The partnering of hospital librarians with other hospital departments to provide consumer health services is described in Chapter 14, where the author also offers an in-depth look some of the health literacy initiatives that are taking place at one teaching hospital.

The numerous intervention programs for professionals engaged in health literacy efforts are presented in Chapter 15.

Examples of health literacy collaborations are provided in Chapter 16, including examples from New York City. The authors also discuss how to find funding support for health literacy initiatives.

I would like to thank my co-editors, Lynda and Feleta, and each of the authors who agreed to contribute to *The Medical Library Association Guide to Health Literacy*. We hope this guide will both inform and inspire our colleagues in all types of libraries to help their communities live longer and healthier lives.

Marge Kars

REFERENCES

- Nielsen-Bohlman, Lynn, Allison M. Panzer, and David A. Kindig (eds.). 2004. *Health Literacy: A Prescription to End Confusion*. Committee on Health Literacy, Institute of Medicine. Washington, DC: National Academies.
- Kutner, Mark, Elizabeth Greenberg, Ying Jin, and Christine Paulsen. 2006. *The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy* (NCES 2006-483). U.S. Department of Education. Washington, DC: National Center for Education Statistics.

Health Literacy is defined in the Institute of Medicine report, *Health Literacy: A Prescription to End Confusion*, as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." Health literacy requires a complex group of reading, listening, analytical, and decision-making skills, as well as the ability to apply these skills to health situations. For example, it includes the ability to understand instructions on prescription drug bottles, appointment slips, medical education b The Medical Library Association *Guide to Developing Consumer Health Collections* guides both library graduate school students and seasoned librarians from academic, health sciences, and public libraries, to develop, maintain, nurture, and advertise consumer health collections. This authoritative guide from the respected Medical Library Association covers all that is involved in developing a new consumer health library including: • Conducting community needs assessments and forging. • Plenty more information on finding resources, taking into account the problems with health literacy, is provided, as well. . . . Health literacy arises from a convergence of education, health services, and social and cultural factors. Although causal relationships between limited health literacy and health outcomes are not yet established, cumulative and consistent findings suggest such a causal connection. Approaches to health literacy bring together research and practice from diverse fields. • The event, cosponsored by three regional chapters of the Medical Library Association, preceded their joint meeting in Sacramento, California. An advisory group of library and literacy professionals from the NN/LM Pacific Northwest and Pacific Southwest Regions, along with a second-year National Library of Medicine associate fellow, planned, implemented, and evaluated the symposium. Read more. Article. National library of medicine current bibliographies in medicine: Health literacy. 2000. 2. Kutner M, Greenberg E, Jin Y, Paulsen C. *The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy (NCES 2006-483)*. • 22. American Medical Association Foundation. (2007). *Health literacy and patient safety: help patients understand* (Vol. 2007). Chicago: American Medical Association Foundation. 23. The Joint Commission. • Implementing health literacy universal precautions in your practice requires that all of your staff members "from front office staff to the medical director" know how health literacy affects your patients and consistently work to make health care clearer and easier. Action. Organizational health literacy is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others. The new definitions: Emphasize people's ability to use health information rather than just understand it. Focus on the ability to make "well-informed" decisions rather than "appropriate" ones. Incorporate a public health perspective. Acknowledge that organizations have a responsibility to address health literacy. Why Is Health Literacy Important? media icon Low Resolution V