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Health Literacy

New Directions in Research, Theory and Practice

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Foreword

Richard H. CARMONA¹
M.D., M.P.H., FACS

In 2002 I had the privilege to be nominated by the President of the United States and unanimously confirmed by the U. S. Senate as the United States Surgeon General. Little did I know that health literacy and cultural competence would not only become a significant portion of my portfolio, both would at times dominate every topic in the Surgeon General's portfolio! This is because the Surgeon General has to communicate with the largest medical practice in the nation, at that time more than 300 million fellow citizens as well as a global population of more than seven billion—who are equally interested in what and how America approaches health and disease.

The job description for the Surgeon General is to protect, promote, and advance the health, safety, and security of the United States. As the Surgeon General, I was the commander of the United States Public Health Service Commissioned Corp. But equally, if not more important, I was the chief health communicator for our nation and often the world.

As a result, it became rapidly apparent that health literacy and cultural competence were essential tools as I addressed a wide array of national health, safety, and security issues of relevance to the most linguistically and culturally diverse nation on earth.

The challenge then and today remains how do I summarize, reduce, explain, translate, and deliver the most complex science the world has ever known to the most diverse population in history? How should one impact sustainable individual and population behavioral change that results in improved health, decreased morbidity, mortality, and health costs while improving the quality and quantity of life?

While simply articulated, the aforementioned challenges are extraordinarily difficult to execute even with health literacy and cultural competence expertise. However, these challenges are *impossible* to address *without* the contributions of health literacy and cultural competence practitioners and researchers.

Many disciplines have contributed to the young multidisciplinary field of health literacy. The field of health literacy rightfully morphed into assessing daily health and medical jargon mostly because this essential element enables us to successfully engage each other and our fellow citizens who we have the privilege to serve.

Nevertheless, as the disease and economic burden of the nation continue to increase and politicians stake out their positions based on partisan ideology, the major contributor to the rising disease and economic burden is being overlooked. It is aberrant actions, such as smoking and sedentary behaviors, that often lead to preventable chronic diseases. Currently, from the U.S. federal government budget of about \$3 trillion, approximately one in five dollars is spent on 'health care.' More precisely, most of the money is spent on 'sick care'—about 75¢ to 80¢ of each dollar is disbursed for preventable chronic disease.

¹ 17th Surgeon General of the United States, Distinguished Professor, University of Arizona

Consequently, unless we can successfully use health literate and culturally competent resonant messaging to engage, educate, and inspire our patients to pursue optimal health and wellness, the disease and economic burden will continue to rise irrespective of who is the nation's leader or which party is in power. While challenging enough, the latter tasks become even more daunting when most of a nation's population is health illiterate, as evidenced internationally by 21st century health literacy research.

To address these and other overwhelming challenges, the peer reviewed health literacy literature continues to grow as it appropriately defines the direct relationship between health literacy skills and ultimate health outcomes. Recent research additionally suggests individuals and communities with reasonable levels of health literacy are able to understand and integrate health messaging into their own lives to stay healthy, prevent disease, and recover from illness.

While the health literacy field began with extrapolating data from general literacy programs and lessons from teaching English as a second language as well as the basic seminal work of Len and Ceci Doak almost a half century ago, the evolution of the understanding of health literacy's complexity is now a legitimate science, which is exemplified by this textbook entitled, *"New Directions in Research, Theory and Practice."*

The science of health literacy is robust as it simultaneously evolves and challenges us. While health literacy is the lowest common denominator for all health related communication, its complexity and multidisciplinary nature defies a single equation or explanation.

The chapters in this text begin the journey of dissecting the variables of health literacy to a granular level where more questions are generated and some answers provided.

A future agenda for health literacy is emerging and includes, but is not limited to, leadership, policy, research, and practice—all topics covered in this textbook.

The commitment to become a health literate organization facilitates the education of staff and simplifies navigation through the health care system for our patients. Health organizations must pursue this goal so a culture of health literacy is promulgated. In addition, in certain communities where there is very low health literacy, shared decision making may be needed to meet the unique needs of vulnerable populations.

As much as the understanding and practice of health literacy has progressed, the book identifies an array of gaps that require further research. These areas include, but are not limited to, assessing how to measure the contributions of health literacy, how to best "activate" our patients and populations to effect sustainable positive behavioral change, as well as collaboration with other disciplines such as educational learning scientists and possibly neuroscientists to learn how to maximize the neuroplasticity associated with learning. I dare say that genomics will one day also be a variable we assess to better understand the genetic contributions of learning and behavior!

For those who master health literacy as practitioners or patients, the world of public health and all its aspirations become possible. For in the end, no matter how simple or complex the science, it is translation within a culturally competent, health literate manner that fosters desired, sustainable behavioral changes. The authors have provided us with a provocative and thoughtful next iteration in health literacy science as well as potential applications. This is essential reading for all health practitioners.

Preface

Robert A. LOGAN
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Overview

'New directions in health literacy research, theory, and practice' provides an introduction to health literacy research and practice and highlights similar scholarship in related disciplines. Although the book is intended primarily for health literacy researchers, practitioners and students, the editors suggest the book's diverse topics and approaches are of interest to health care and public health researchers, practitioners, and students in addition to scholars in related fields, such as health communication, science communication, consumer health informatics, library science, health disparities, and mass communication.

Some of the book's chapters on related fields (e.g. shared decision-making, patient engagement, patient activation, health prevention, design science, and mHealth) and related areas (e.g. the U.S. National Cancer Institute's Health Information National Trends Survey) also summarize some current research within each area. The book's editors and authors hope readers will mine individual chapters to write backgrounds for literature reviews well as to plan health literacy (and related) research and practice initiatives as well as interventions.

Organization and Chapter Contents

The book is organized as such: the initial chapter explains the still-evolving definition of health literacy; three chapters discuss developments and new directions in health literacy research; two chapters are devoted to developments and new directions in health literacy theory; two chapters detail health literacy interventions for vulnerable populations; four chapters cover health literacy leadership efforts; six chapters describe developments and new directions in disciplines that are similar to health literacy; and six chapters portray diverse health literacy practices. A preface from Richard Carmona, the former U.S. Surgeon General, is included in addition to this forward.

More specifically, in the book's first chapter Sorensen and Pleasant outline some conceptual differences in health literacy definitions and suggest current disagreements provide a foundation for the evolution of a more comprehensive health literacy definition. Sorensen and Pleasant explain that how health literacy is defined remains a foundational issue for health literacy researchers and practitioners.

The chapters devoted to developments and new directions in health literacy research feature three different themes. The chapter by Nguyen, Paasche-Orlow, and McCormack notes the recent progress and challenges to provide more empirical rigor within existing health literacy measures. The authors also discuss the Health Literacy Tool Shed (that they helped develop) which critiques health literacy tools and enables researchers to assess diverse health literacy measures. The chapter is especially recommended for health literacy scholars who are writing the methods section within a

research paper. The chapter by Pelkian and Ganahl summarizes the development, psychometric properties, and results from recent health literacy population surveys within some European Union (EU) nations. Pelikan and Ganahl note the EU survey is integrative and based on 12 published models and 17 definitions of health literacy. The authors provide some specific suggestions to future researchers to measure health literacy in general populations. They report the survey's findings suggest low but varying health literacy levels among the participating nations. In this section's third chapter, Rudd identifies some gaps within the health literacy research literature as well as in health literacy practice. In an environmental scan of current research and practice, Rudd furnishes important issues for future health literacy researchers to consider including increased attention to the institutional and system wide norms, policies, and regulations that facilitate or impede access to health information, services, and care. The chapter is especially recommended for health literacy scholars who are writing the literature review section within a research paper.

The chapters devoted to developments and new directions in health literacy theory cover health literacy and the arts, and the conceptual crossroads between health literacy and health disparities research. Ike, Parker, and Logan describe research that suggests the arts are associated with better health outcomes and explain how this correlation has important implications for health literacy research and practice. The chapter additionally provides a theoretical framework that suggests why the arts may be therapeutic. In the second chapter within this section, Logan argues while health disparities and health literacy research are different disciplines, they share common conceptual foundations. The chapter suggests there are vacuums in current research knowledge that need attention – especially regarding the integration of health literacy and health disparities research to assess the social and structural determinants of health.

The two chapters devoted to health literacy interventions for vulnerable populations discuss initiatives within diverse community settings. A chapter by Smith and Carroll summarizes findings from U.S. social work interventions to improve maternal health within vulnerable populations where health literacy (in conjunction with other variables) is associated with improved health outcomes. Smith and Carroll's comprehensive findings yield an intricate web of interactions that occur among health literacy with other social, structural, cultural, family, and individual determinants of health. In this section's second chapter, Pleasant describes the Canyon Ranch Institute's (CRI) health literacy/integrative health interventions, which serve vulnerable populations in the U.S. and internationally. While Pleasant covers several CRI projects, he highlights a health literacy/theater for health intervention (utilizing community participation) within a low-income area of Lima, Peru that fostered favorable health outcomes.

Four chapters describe an array of health literacy leadership efforts. Hernandez, French, and Parker outline some of the initiatives launched by the U.S. National Academies of Sciences, Engineering, and Medicine's Roundtable on Health Literacy since its inception in 2004. The authors provide an overview of the Roundtable's contributions to health literacy. Hernandez, French, and Parker note the Roundtable has focused on evidence-based health literacy approaches that foster high-quality, patient centered care. Baur, Harris, and Squire explain the developments that prompted the 2010 U.S. National Action Plan to improve health literacy and note how the planning and activities associated with the effort became a model for positive organizational change. Brach describes the advancement of now-widely used criteria to assess and implement health literacy initiatives and perspectives within health care organizations. Brach explains the progress of health care organizations as they journey from implementing

discrete health literacy initiatives to adopting a systems perspective focused on becoming health literate organizations. Besides providing some background about the criteria's development, Brach profiles some implementation efforts within three U.S. health care organizations (Carolinas Healthcare System, Intermountain Health, and Northwell Health). In this section's last chapter, Aldoory tracks health literacy higher education and related professional training efforts in the U.S. Aldoory's overview is one of the first efforts to describe health literacy higher education activities; she provides a case example that notes how policy developments in one U.S. state (Maryland) impacted the role of health literacy in professional higher education.

The six chapters devoted to developments and new directions in disciplines similar to health literacy describe six separate fields that provide collaborative opportunities for health literacy researchers and practitioners. Hibbard describes some similarities and differences between patient activation and health literacy research. Hibbard also provides a helpful summary of patient activation research in the U.S. and other nations. Stacey, Hill, McCaffery, Boland, Lewis, and Horvat review shared decision making's theoretical and empirical underpinnings and note the research's implications for health literacy scholarship. Stacey, Hill, McCaffery, Boland, Lewis, and Horvat provide international examples and suggest the integration of health literacy principles is important to develop interventions that facilitate shared decision making and essential to overcome the inequalities among patients with varying health literacy levels. Krist, Tong, Aycock, and Longo describe recent research efforts to engage patients in decision-making and behavior change to promote health care prevention. The authors note the theoretical underpinnings of engagement, the systems required to better support patient engagement, how social determinants of health influence patient engagement, and practical examples to demonstrate approaches to better engage patients in their health and wellbeing.

In one of the other three chapters within this section, Neuhauser provides an introduction to participatory design theory and endorses more collaboration between participatory design and health literacy researchers. Neuhauser supplies some research tips and case examples for researchers, practitioners, and policymakers. Hesse, Greenberg, Peterson, and Chou explain that the U.S. National Cancer Institute's Health Information National Trends Survey (HINTS) provides a downloadable, generalizable data set about how consumers utilize cancer health information resources. Hesse, Greenberg, Peterson, and Chou provide some HINTS-derived research that addresses consumer health engagement, consumer health informatics, consumer health awareness, and media utilization. In the last chapter in this section, Kreps describes the interactions between mHealth, health communication, consumer health informatics, and health literacy research. Kreps also addresses the use of mHealth in successful consumer health interventions and notes its potential for future use in health literacy initiatives.

The book's remaining six chapters provide a range of innovative health literacy practices. In the first of two chapters (by a team of international authors from diverse nations), Rowlands, Dodson, Leung, Levin-Zamir et. al. discuss how diverse global health systems and policy development provide opportunities for health literacy research, theory, and practice. The authors suggest a health literacy framework provides a pragmatic way to address health inequities and monitor progress across policy domains. In their second chapter, Levin-Zamir, Leung, Dodson and Rowlands et. al. note how individual, family, community, and cultural health challenges within diverse international settings impact health literacy initiatives as well as provide opportunities for health literacy researchers and practitioners. Among other issues, the authors note cur-

rent cultural competence gaps among international health care providers exemplify how capacity building in health literacy is critical to improve a nation's health care delivery system. In the third chapter within this section, Whitney, Keselman, and Humphreys provide an overview of how libraries and librarians have contributed to health literacy practice and research. Whitney, Keselman, and Humphreys explain libraries often provide advantageous settings for health literacy initiatives and the authors encourage the collaborative participation of libraries and librarians in future health literacy research.

In the three remaining chapters within this section, Villaire, Gonzalez, and Johnson describe how health literacy initiatives contribute to innovative approaches in chronic disease management. Villaire, Gonzalez, and Johnson add the inclusion of health literacy assessment tools optimizes validation efforts within chronic disease management research. Kurtz-Rossi, Rikard, and McKinney describe how the U.S.-based Health Literacy Discussion List (which is an interactive listserv) yields ongoing data about contemporary topics of interest to health literacy practitioners. The authors' findings suggest the Health Literacy Discussion List provides a platform to share information and resources, announcements and calls for action, technical assistance, and professional discourse. In the book's final chapter Roberts, Callahan, and O'Leary describe the U.S.-based, Health Literacy Media's efforts to elevate health literacy via the use of social media. Roberts, Callahan, and O'Leary find social media are an effective mass communication tool for health promotion and health literacy initiatives. The authors provide tips for practitioners to use in future social media/health literacy efforts intended for vulnerable populations as well as other audiences.

Diversity of Nations, Institutions, and Universities Among the Book's Authors

The book's authors represent diverse nations including: Australia; Brazil; Canada; China; Denmark; India; The Netherlands; United Kingdom; and the United States.

Represented international colleges and universities include: Boston College; Boston University; Emory University; George Mason University; Harvard University; Michigan State University; Tufts University; Virginia Commonwealth University; University of California-Berkeley; University of Maryland, University of Oregon; University of Washington; Mayo Clinic College of Medicine; University of Ottawa; University of Vienna; University of Newcastle; La Trobe University; Aarhus University; Hong Kong Polytechnic University; University of Haifa; Manipal University; Brazilian National School of Public Health; and Deakin University.

Represented international health care institutions and organizations include: the Global Health Literacy Academy; International Health Literacy Association; Canyon Ranch Institute/Health Literacy Media; RTI International; U.S. National Library of Medicine; U.S. National Cancer Institute; U.S. Office of the Surgeon General; Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services; U.S. Agency for Healthcare Research Quality; U.S. National Academies of Sciences, Engineering, and Medicine; Mayo Clinic; Clalit Health; Institute for Healthcare Advancement; Victoria State Department of Health and Human Services; Fred Hollows Foundation; Bundesministerium fur Gesundheit und Frauen; and the Community Health and Learning Foundation.

Background

Overall, 'New directions in health literacy research, theory, and practice' took about 26 busy months from start to finish. It began during Elliot Siegel's consultation visit to the

U.S. National Library of Medicine (NLM) in spring 2015 when he told Rob Logan about a publishing initiative from IOS Press called ‘Studies in Health Technology and Informatics.’ Logan responded by preparing an outline of 26 chapters designed to cover contemporary health literacy theory and research as well as some developments in related disciplines in the U.S. and around the world. In the outline, Logan suggested the book’s eventual title and recommended that he co-edit the volume with Siegel, NLM’s emeritus Associate Director of Health Information Programs and Outreach.

To Logan’s delight, IOS Press quickly embraced the outline’s plans and initial invitations were sent to selected authors in summer 2015. Twenty-two months later, Logan and Siegel are pleased to report that 23 of the 24 of the current book’s chapters are authored or co-authored by the originally invited contributors – and 23 of the 24 topics are either identical or highly similar to the ideas suggested within the initial invitations. The book’s editors note the impressive participation by the original authors suggests the interest and pent-up demand to write a book about diverse aspects of health literacy research and practice. To put this another way, Logan and Siegel benefitted from an unprecedented rate of contributor acceptance, perseverance, cooperation, and occasional enthusiasm.

Most of the book’s chapters were written and current as of late fall and winter 2016-17. The book was edited to foster some consistency in the quality of writing among and between chapters, which befits the book’s health literacy focus. Yet, as explained in the first paragraph, the book was edited for health literacy researchers and practitioners rather than the general public.

Full disclosure: some of the book’s chapters have been published in *Information Services and Use* with the consent of IOS Press (which is the publisher of the latter journal, this book, and the ‘Studies in Health Technology and Informatics’ initiative). Previous NLM contracts helped support the research presented in the chapter by Sandra Smith and Lauren Carroll and the development of the Health Literacy Tool Shed (described by Nguyen, Paasche-Orlow, and McCormack in their chapter).

Appreciation

Logan and Siegel are proud to have been associated with this book’s development. We especially thank Betsy Humphreys MLS, who was NLM’s acting director at the time of the book’s inception (and co-authored a chapter) as well as Patricia Flatley Brennan Ph.D., who became NLM’s director in September 2016. Brennan and Humphreys graciously supported Logan’s time commitment to provide original contributions and serve as the book’s co-editor.

The editors also gratefully acknowledge the interest in this book’s development from diverse members of the U.S. National Academies of Sciences, Engineering, and Medicine’s Roundtable on Health Literacy and the new International Health Literacy Association. Some of the ideas for the book’s topics (as well as some authors) came from members of these organizations. In addition to our kudos to all of the book’s authors and Kairi Look, Paul Weij, Kim Willems, and Arnoud de Kemp @ IOS Press, the editors thank Rachel Fudge (a free lance editor in San Francisco, CA.), for her assistance in the conversion of some manuscripts to meet IOS Press’ technical publication requirements.

We hope ‘New directions in health literacy research, theory, and practice’ attains the 2015 request to the initial invitees to ‘create a gem.’

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