

**ROLES AND RESPONSIBILITIES
OF LIBRARIES IN INCREASING
CONSUMER HEALTH LITERACY
AND REDUCING HEALTH
DISPARITIES**

ADVANCES IN LIBRARIANSHIP

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ADVANCES IN LIBRARIANSHIP VOLUME 47

**ROLES AND
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HEALTH DISPARITIES**

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INTRODUCTION

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CHAPTER 1

INTRODUCTION: LIBRARIES AND LIBRARIANS AS AGENTS OF HEALTH INFORMATION JUSTICE

Beth St. Jean, Paul T. Jaeger, Gagan Jindal and
Yuting Liao

ABSTRACT

This chapter introduces the focus of this volume – the many ways in which libraries and librarians are helping to increase people’s health literacy and reduce health disparities in their communities. The rampant and rapidly increasing health injustices that occur every day throughout the world are, in large part, caused and exacerbated by health information injustice – something which libraries and librarians are playing an instrumental role in addressing by ensuring the physical and intellectual accessibility of information for all. This chapter opens with an introduction to the central concepts of health justice and health information injustice, focusing on the many information-related factors that shape the degree to which individuals have the information they need to be able to have a sufficient and truly equitable chance to live a long and healthy life. Next, the authors present a timely case study to emphasize the importance of health information justice, looking at the dire importance of health literacy as we navigate the COVID-19 pandemic. The authors then provide a brief glimpse into their 13 contributed chapters, grouped into five categories: (1) Public Libraries/Healthy Communities; (2) Health Information Assessment; (3) Overcoming Barriers to Health Information Access; (4) Serving Disadvantaged Populations; and (5) Health Information as a Communal Asset. In conclusion, the authors discuss their aims for this

Roles and Responsibilities of Libraries in Increasing Consumer Health Literacy and Reducing Health Disparities

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volume, particularly that readers will become more aware of librarians' efforts to address health disparities in their communities and excited about participating in and expanding these efforts, moving us closer to health justice.

Keywords: Consumer health information justice; libraries; health literacy; health justice; health disparities; consumer health information behavior

INTRODUCTION

The aim of this volume is to bring together the voices of researchers and librarians whose work focuses on the many ways in which libraries and librarians are helping (and can help) to improve consumer health literacy and decrease health disparities in their communities. A central concept underlying our motivation for undertaking this volume is health justice, and more specifically, health information (in)justice (St Jean, Jindal, Liao, & Jaeger, 2019a, 2019b). Achieving health justice requires that we ensure that every individual has a sufficient and equitable capability to be healthy (Venkatapuram, 2011). Evidence that health justice does not exist, both in the USA and abroad, abounds. Recent studies, such as Chetty et al. (2016) and Olshansky et al. (2012), have found that people who have higher incomes, who have greater educational attainment levels, and who are white live, on average, 10–15 years longer than people who are not so advantaged. Both Chetty et al. (2016) and Olshansky et al. (2012) further found that these disparities in life expectancy have actually been continuing to grow over time.

One of the contributing factors to health injustice that is of particular relevance to this volume is health information injustice. People who do not have sufficient and equitable access to resources and opportunities, such as information, do not have a sufficient and equitable chance to live a long and healthy life. Many types of information-related factors are at play here, including one's awareness of potential sources of trustworthy information; one's physical and intellectual access to these sources; one's awareness of their information needs; one's physical, financial, intellectual, etc. ability to act on these needs; one's information seeking and (equally, if not more, importantly) avoidance strategies; and, particularly important, the actionability of available information for a given individual, particularly in light of the social determinants of health; that is, the "conditions in which persons are born, grow, live, work, and age" (World Health Organization (WHO), 2011, p. 2).

Information, and the libraries and librarians that help people find, understand, and use it, have the potential to move us closer to health information justice, and thus, health justice. In this volume, we have the opportunity to learn directly from both librarians and researchers about the many ways in which libraries and librarians are working with their communities to improve their health literacy ("the capacity to obtain, process, and understand basic health information and services needed to make appropriate health care decisions" (Ratzan & Parker, 2000)) and to decrease health disparities in their communities.

In the following section, we present a case study focused on the current pandemic—COVID-19, highlighting the central importance of health literacy amid the plethora

of mis- and dis-information that pours into our lives on a daily basis, leading to dire consequences for some individuals, particularly those who are deceived and subsequently act on bad information. Next, we introduce the themes around which the chapters in this volume are organized, and provide a brief glimpse into each of them. To conclude the chapter, we discuss our aims for this volume.

THE DIRE IMPORTANCE OF HEALTH LITERACY AMID THE COVID-19 PANDEMIC

There's a very good chance you're not going to die.
– President Donald Trump, February 25, 2020

(Bump, 2020)

When we originally conceived of the idea of this book, we of course had no inkling that once the final versions of the chapters were being submitted, the world would be in the midst of its first viral pandemic in more than 100 years. As the novel coronavirus (COVID-19) has quickly spread throughout a very interconnected globe, the importance of information literacy has been brought into the stark relief of life and death decisions. When faced with a potentially life-threatening viral infection without a cure blazing across the planet, health information literacy could not be more important.

Thus far, the lack of health information literacy has been on prominent display pretty much everywhere. The virus quickly became an opportunity for bad actors and well-meaning but poorly informed actors alike to spread harmful, false claims related to the virus. Through social media platforms, bad actor governments, like Russia and Iran, were working overtime to sow disinformation that the US government had created the virus or, inevitably, that billionaire George Soros had created the virus. Though the virus that hit New York City and the rest of the United States largely spread by way of Europe, it originated in China (Mount Sinai, 2020); meanwhile, the Chinese government was claiming that the virus originated in several other places, including the USA. Jerry Falwell, Jr, the President of Liberty University, on the other hand, told any media outlet that would listen that the virus was created by North Koreans.

The rightwing infosphere in the USA was somehow simultaneously claiming that the virus was a Chinese bioweapon, that it was no more harmful than the common cold, and it was only being hyped to hurt President Trump's reelection efforts. In the United States, many state and local politicians, in their official capacities, have asserted that the virus is a hoax or, at the very least, overhyped and encouraged ignoring Centers for Disease Control guidance about limiting the spread of the virus. The President of the United States even suggested that people ingest household disinfectants – which are highly toxic and would not help with the coronavirus – as a way to battle the virus. Parallel behaviors by political leaders were occurring in many other nations as well.

Random online commentators were disseminating advice that garlic, zinc, nasal spray, vitamin C, ultraviolet light, and, also inevitably, powdered rhino horn were cures for the virus, as well as admonitions not to eat in Chinese restaurants

or open mail sent from China. Consider that the following is only a small slice of dangerously bad information making the rounds of email, text messaging, and social media as of March/April/May 2020:

- The rightwing extremist group QAnon was pushing that chlorine should be used for hand washing and gargling.
- Televangelist Jim Bakker was selling “silver solution” made from colloidal silver as a virus cure-all.
- Conspiracy monger and professional reality denier Alex Jones was selling nutritional supplements and hygiene products that he claims will protect you from the coronavirus.
- A rumor began in Europe and quickly spread that 5G wireless networks were somehow spreading the virus.
- So many people in France were believing the claim that snorting cocaine cured the virus that the French government felt compelled to issue a formal statement that it was not true.

Clearly, the first could be quite fatal advice, while the other four are just nonsense, and the last one is illegal as well. Much of the problem with the spread of this kind of false information is that it is on social media and on direct messaging services (SMS text, email, WhatsApp, and Tik Tok), where much of the false information is being sent as graphical images to avoid being caught by keyword checks. Perhaps most astoundingly, the President of the United States even suggested that people ingest household cleaning products to kill the disease (and possibly themselves).

Even in somewhat less terrifying times, people do not naturally have a strong record with making good choices with information online. Social media companies heavily promote bad information by design, as their algorithms give priority to controversial topics to generate views and thereby revenue (Badia, 2019). Emotional content is far more memorable to most people than are facts or statistics (Sharot, 2017), and spreading fear about a new virus certainly qualifies as emotive. In their algorithm-fueled filter bubbles, many users had no idea that they were only receiving bad information about the virus (Del Vicario et al., 2016). As governments and individuals have become increasingly talented at creating realistic fake news, whole online businesses, like Channel23News, exist to allow users to create genuine-looking fake news to populate into social media. Even actual experts in epidemics were getting caught by misinformation, with some of them retweeting false information from Russian disinformation campaigns about the virus (Bellware, 2020).

As long as there has been communication in any form, information could be manipulated and used to deceive, but it is simply so much easier now (Burkhardt, 2017). Any actor online can take advantage of this situation to create bad information and try to get it in front of the greatest number of people as fast as possible (Bauman, 2020). Lies are now firmly rooted in social media before experts are even aware that the lies exist, with social media companies having little incentive to do anything other than promote usage of the content on their platforms, no

matter how pernicious it may be. Even on the rare occasions that social media companies try to curb the spread of bad information, as they are currently attempting to do with the novel coronavirus, their own efforts cannot keep up with the unceasing cascade of bad information that defines their products and their usage.

Social media platforms and messaging services are now one of the primary sources – if not the primary source – of political and current events information for the majority of Americans as well as people in many other nations, and many individual social media accounts have larger numbers of readers than the major news organizations (Allcott & Gentzkow, 2017; Gottfried & Shearer, 2016). People relying on social media for their political and current events information, unfortunately, do not generally understand the ways in which they receive that information. A wide range of research across many academic fields has demonstrated that human brains are not especially good at dealing with this infinite abyss of information, generally opting toward information that the user already agrees with and information that is sensationalist (for summaries of such research, see Bauman, 2020; Carr, 2011; Levitin, 2017). Americans are most likely to believe misinformation about political actors (Humprecht, 2019) and are most likely to be influenced by disinformation encountered passively on social media (Groshek & Koc-Michalska, 2017). In combination, this does not bode well for social media as being a productive learning tool, even in times of less excitement.

Overwhelmingly, users do not understand the role, or even the existence, of algorithms in determining the information that they are exposed to and share with others through newsfeeds, search engines, and even advertising (Badia, 2019; Eslami et al., 2015; Proferes, 2017; Rader & Gray, 2015). In most cases, the user now sees what the algorithm thinks the user would like to see, based on all the information that the algorithm has about the user, continually reinforcing the messages the user gets and further limiting the range of information that is presented to them. As a result, political and current events information is not equipped to educate, but is instead tailored to perpetuate any beliefs in misinformation.

Even when the social media companies that are so reliant on algorithms for delivering content to users attempt to limit fake news, misinformation, and algorithmic biases, their own creations are not able to make it happen effectively. Their systems are not constructed to make evaluative decisions about abstract concepts like correctness or accuracy, which are at least at this point entirely human skills; the systems can be programmed to prevent spread of certain images or words, but the systems have no sense of the reasons behind such decisions (Badia, 2019). In short, the primary source of political and current events information for huge portions of the population simply cannot provide only truthful or accurate information.

This environment can challenge even people with high levels of awareness of all of these issues, as reflected by the aforementioned example of infectious disease experts repeating false information about the virus being spread by the Russian government. Adding a situation in which everyone in the world wants more information to this environment is bound to result in a festival of challenges to health information literacy. An example of all of these issues in action in this crisis was a hashtag “#Plandemic,” which helped spread a video of the

same title that claimed the virus was manufactured by Bill Gates, Dr. Anthony Fauci of the National Institute of Allergy and Infectious Diseases, and others in order to profit off a vaccine and allow the government to track every individual in the country by implanting chips in them, and that beaches were closed because seawater is the cure for the virus. Even with measures in place to try to stop the spread of virus misinformation, the Plandemic video was viewed more than 8 million times before being pulled down by social media companies.

For many of the most vulnerable populations in terms of information, the pandemic has added another layer of barriers to access and literacy. With the closure of a great many public spaces to limit spread of the virus, physical access to many public libraries has disappeared. With the disappearance of that access, not only has access to physical collections been halted, many individuals who relied on the library for their access to computers and the Internet – especially for health information – have lost their link to the online world and the librarians who could help them navigate that world. For many people, most especially those of lower socio-economic status being hit especially hard by the virus, the physical closure of libraries seismically shrinks the information available in their world, highlighting both the roles of libraries in ensuring health information justice through access, literacy, and education and the catastrophic impacts of the glaring gaps in health information justice in society.

ABOUT THE VOLUME

This volume focuses on the many ways in which libraries and librarians are working to improve the health literacy of their community members and to decrease the health disparities and health information injustice that pervade many of their communities. The 13 chapters in this volume have been organized into the following themes: (1) Public Libraries/Healthy Communities (Chapters 2–5); (2) Health Information Assessment (Chapters 6 and 7); (3) Overcoming Barriers to Health Information Access (Chapters 8 and 9); (4) Serving Disadvantaged Populations (Chapters 10–12); and (5) Health Information as a Communal Asset (Chapters 13 and 14). In our final chapter of the volume (Chapter 15), we provide a brief recap of the contributed chapters, summarizing libraries' roles in helping to improve consumer health literacy and decrease health disparities, and discuss their new and continuing roles in this regard in the midst of COVID-19. Dr Beth Barnett also provides her perspectives, as a Board Certified Patient Advocate, on the volume, and we conclude the chapter with a call to action to ensure health information justice and optimal health outcomes for all. In the following subsections, we briefly describe each of the chapters that comprise this volume.

Public Libraries/Healthy Communities

Some of the chapters in this volume focus most centrally on the important roles that libraries and librarians play in ensuring the health literacy and the health of their communities. This theme covers the chapters written by: (1) Catherine Arnott Smith, Alla Keselman, Amanda Wilson, and M. Nichelle Midón;