Health literacy and empowerment in the COVID-19 era

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Abstract. The COVID-19 pandemic presented a teachable moment to empower citizens to assess and apply information to protect their health by promoting critical health literacy. Most Americans took preventive measures, suggesting some overall increase in critical health literacy around infectious disease. Simultaneously, however, a torrent of misinformation, disinformation and malinformation intentionally buried facts, sewed doubt and confusion, promoted lies and conspiracies, and undermined health authorities and institutions. The authors discuss how this 'infodemic' rose from previously localized, unconnected antivaccination, anti-government, and anti-science groups galvanized by the pandemic. Prominent politicians seeking political gain lent the power of their offices to the movement, layering a 'polidemic' onto the infodemic and overwhelming inconsistent public health messaging. Even those with strong health literacy skills were challenged. Millions were misled to over-confidently self-manage their risk, revealing the possibility and perils of empowerment in the absence of critical health literacy skills – negative empowerment. The roots of resistance to the government response to COVID-19, and conditions that fostered its influence are examined, followed by recommendations to position health literacy scholars and practitioners to better meet communication challenges and opportunities in future crises.

Keywords: COVID-19, health literacy, critical health literacy, negative empowerment, misinformation, malinformation, infodemic, polidemic

"Health literacy could play a significant role in containing the virus by empowering citizens to understand and apply information provided by government sources and health authorities" [1].

1. Introduction - COVID-19: a missed opportunity to promote health literacy and empowerment

Andrew Pleasant framed the 2001 Anthrax bioterrorism scare as an opportunity to promote health literacy in all its aspects [2]. Similarly, on a global scale, the COVID-19 pandemic presented, and continues to provide, an opportunity to promote health literacy, especially critical health literacy, along with science literacy, civic and cultural literacy, and thereby empower citizens to understand, assess, and apply information to protect and promote individual and public health.

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Table 1 COVID-19 Lexicon

Term	Definition
Infodemic	An over-abundance of information — some accurate and some not — rendering it difficult to find trustworthy sources of information and reliable guidance [38].
Infodemiology	This term was first used in the context of analyzing the "supply side" (what is being published on the Web) in 2002. Infodemiology has broaded to refer to the science of distribution and determinants of information in an electronic medium, specifically the Internet, or in a population, with the ultimate aim to inform public health and public policy [53].
Infoveillance	Using infodemiology data for surveillance purposes has been called "infoveillance" [53].
Polidemic Disinformation	A phenomenon that combines politics and epidemics [15]. Disinformation is deliberately created to mislead, harm, or manipulate a person, social group, organization, or country [54].
Misinformation	Misinformation is false, but not created or shared with the intention of causing harm [54].
Malinformation	Malinformation is based on fact, but used out of context to mislead, harm, or manipulate [54].

Although the empirical evidence is not robust, health literacy (particularly critical health literacy) and empowerment are linked in the literature and discourse. Empowerment has been described as the ultimate goal of health literacy in both clinical practice and public health [3].

By definition, a critically health literate person obtains, understands, assesses, and acts on information to exert greater control over life events and situations [4]. In a clinical setting, functional literacy is a prerequisite to critical health literacy, and a patient demonstrates health literacy and empowerment by compliance. This view focuses on reading health information and following a clinician's instructions. From a public health standpoint, by definition, health literacy and empowerment converge in critical health literacy. This perspective emphasizes the social determinants of health. Critical health literacy (health empowerment) is indicated by personal, political, and social actions.

While the authors have argued with Nutbeam that health empowerment is intrinsic to critical health literacy, others suggest the two constructs are separate [3]. Schulz and Nakamoto suggest that empowerment for health, like empowerment in the workplace, simply implies a willingness to act, along with permission and information (from clinicians) to do so [5].

In this paper, the authors reveal the unexpected negative empowerment arising from an 'infodemic' surrounding COVID-19, the primary tool of resistance to public health efforts in the U.S. The actions taken by millions in response to the infodemic demonstrate that in the absence of critical health literacy, health related disinformation can empower as well as facts, with deleterious effects on personal and public health.

The authors discuss the effectiveness of public health efforts to contain COVID as the pandemic increased health literacy demands for citizens, journalists, commentators, and politicians alike. 'Infodemic' is one of many new terms and concepts introduced by the pandemic. Table 1 describes seven types of false health information at the foundation of the COVID-19 infodemic.

A discussion of critical health literacy and empowerment is followed by delineation of outcomes of the politicization of COVID-19 and the U.S. government's response. The authors discuss how negative empowerment led millions of citizens to make often-fatal healthcare decisions and to actively participate in political action and policy debates.

The paper closes with a review of factors that enabled the infodemic to inoculate segments of the public with doubt and mistrust of health authorities and institutions, along with suggestions of what to do now in preparation for future public health crises.

1.1. Opportunity presented itself at the onset of COVID-19

To provide some initial background, by February 2020, COVID-19 had captured the U.S. public's attention. People were actively seeking information and advice. Health literacy advocates had a role model in Anthony Fauci M.D., then director of the National Institute of Allergy and Infectious Diseases and chief medical advisor to the President, who demonstrated how to promote science literacy during the Anthrax scare, and outbreaks of Ebola and Zika [2]. Daily news conferences featuring Dr. Fauci and other infectious disease experts were broadcast nationally. Then-President Donald Trump and political leaders were actively engaged. Then-Vice-President Mike Pence was leading a national response. Large pharmaceutical competitors and international science labs were collaborating to fast-track development of rapid testing and a vaccine. Initially, the U.S. seemed poised to adopt preventive behaviors to contain the virus and limit its damage.

1.2. Public health efforts were effective; health literacy increased for some

By March 2023, more than 672 million shots had been delivered in the U.S., blunting the worst effects of the virus [6]. Indeed, most Americans had adopted preventive measures; 73 percent of those eligible (230 million individuals, including 94 percent of seniors 65+) obtained the primary series of the vaccine [6]. Many Americans began wearing masks, socially distancing, and working from home during lockdowns. These actions were taken despite inconsistent communication by government sources and health authorities. This level of awareness and preventive action suggests that overall critical health literacy related to infectious disease increased nationally to some degree.

While the virus remains a danger to the most vulnerable, especially seniors, U.S. President Joseph Biden announced plans to officially end the COVID-19 public emergency on May 11, 2023 [7,8]. President Biden declined to veto a bill passed by Congress over his objections ending the emergency effective April 10, 2023 [9]. Ramifications of this official end to the pandemic in the U.S. will be complex and wideranging [10,11]. The new phase of pandemic recovery will present new challenges to health literacy in all its aspects.

1.3. Health literacy demands increased

Meanwhile, the unpredictable progress of the pandemic, data lags, and unknowns hampered a governmental response, deepened historical controversies over the role of public health, and fueled conspiracy theories surrounding vaccines [12]. In an environment of fear and confusion, the deluge of rapidly changing and often contradictory information exceeded the capacities of some citizens including journalists, commentators, influencers, activists, and politicians, to assess quality information and sources. Carpiano and associates suggest the evolution and expansion of anti-vaccine activism led millions of Americans to believe and act on misinformation, disinformation, and malinformation from "health freedom" and

"medical freedom" advocates in concert with some political leaders in all levels of government whose desired outcome was political advantage rather than public health [13].

During the pandemic, the infodemic's diffusion paralleled a counter scenario where critical health literacy and empowerment efforts fostered healthy behaviors. Two scenarios occurred simultaneously; one reflected the inclusion of critical health literacy as an integral part of empowerment efforts while negative empowerment efforts challenged health literacy initiatives. The paradox of these differing approaches suggests the importance of health literacy in resolving future public health crises, as the authors will discuss.

2. Extremist politics, fear and scientific uncertainty produced an infodemic

"An infodemic is an overflow of information of varying quality that surges across digital and physical environments during an acute public health event. It leads to confusion, risk taking, and behaviors that can harm health and lead to erosion of trust in health authorities and public health responses" [14].

The COVID infodemic fueled by politicians seeking political gain, might also be termed a 'polidemic,' which combines politics and an epidemic [15]. Resistance to public health measures entwined with anti-government sentiment is not new. Anti-government and anti-vaccination movements have used the same methods and messages for more than 140 years in the U.S. starting with a smallpox outbreak during the Civil War [16]. Trust in public health authorities and public acceptance of federal agencies' preventive and protective recommendations has waxed and waned with these movements.

David Kessler M.D., former head of the U.S. Food and Drug Administration, who led the development of testing and vaccines in the Biden administration, noted parallels between infodemic efforts and disinformation campaigns surrounding tobacco cessation [17]. Historically, resistance groups have been small, locally focused, and unconnected. Health authorities have been largely unaware or dismissive of such resistance as noise from the fringe [13,18].

2.1. "Pandemics generate fear, anxiety and paranoia that can lead to ... discrimination, scapegoating and predation on the vulnerable" [19]

Yet, the COVID-19 pandemic provided a common focus for previously disparate factions and movements. The Internet and social media brought them from the fringe to the mainstream combining and broadening their audiences and organizing them into a cross-pollinating national network. Despite efforts from some social media companies to remove it from their platforms, misinformation and disinformation went viral. The nation was injected with doubt and distrust [13].

The infodemic focused, fostered, and tapped existing anti-government sentiment and long-established networks of anti-science, anti-vaccination, anti-government groups like the national and international "Freedom Keepers" chapters. Elected public officials at all levels of government produced, and as of this writing sustain, the COVID-19 infodemic to downplay the severity of the pandemic, control the narrative around the origins and spread of COVID-19, undermine the Centers for Disease Control and Prevention, deflect blame, and to seek revenge on political opponents [13,20].

Lies and conspiracies spread and were amplified through social media, and some news outlets and commentators. Then-President Trump, with all the media attention the office draws, became a leading source of miracle cures, off-label treatments, and conspiracies [21]. Major media and investigative journalists, and to a lesser degree, social media platforms debunked conspiracies, exposed lies and lack

of evidence, and promoted testing and vaccination. Despite their efforts within some U.S. population segments, evidence-based facts were insufficient to overcome confirmation bias, naive realism - overconfidence in one's pre-existing beliefs and interpretation of evidence, and the widely shared false narratives from usually credible sources, such as the office of the President, and members of Congress [22].

Similarly, public health measures to mitigate the spread of the disease, such as vaccination, masking, distancing, and closures, were framed as tyranny [23]. Resisters were lauded as patriots [24].

While purveyors of the COVID-19 infodemic are likely unfamiliar with health literacy terms and concepts, their tactics outlined in Table 1 aim to overwhelm critical health literacy, science literacy, civic and cultural literacy. The infodemic has been especially effective in populations with low functional literacy and limited access to health care, and in U.S. counties that voted strongly Republican in 2020 [7]. Indeed, a recent Cochrane Library review of studies on the efficacy of interventions to encourage masking found the evidence inconclusive. The Cochrane review made popular headlines misrepresenting it as a study of the efficacy of masking, and misinterpreted its findings as definitive evidence that health masks do not work; and further evidence of government public manipulation [25].

3. Empowerment without health literacy

"Addressing misinformation not only requires imparting knowledge but also correcting mistaken beliefs; research has shown that people who are misinformed can be very persistent in their beliefs. Persistence increases when information (accurate or not) is consistent with pre-existing beliefs or contributes to the coherence of a story or schema, when it is perceived to be widely shared and when the source is perceived to be credible" [26].

By definition, empowered individuals do not passively receive, accept, and comply with information and advice. Rather, they seek to make personal meaning from the information, make choices, and take action to affect current real-life circumstances [5]. Empowered individuals transform choices into desired actions and outcomes [3,27].

Yet, empowerment without a range of health literacy skills can lead to uninformed or misinformed potentially dangerous health decisions [5,26]. Due to the COVID infodemic, a large segment of the population currently seems empowered without health literacy. Defiance of public health measures has been made a symbol of independent thinking and loyalty to a former President [16].

Personally and socially motivated by disinformation and overconfidence, many are actively participating in policy making through political and social action and choosing to problematically self-manage their health [5].

Yet, health literacy scholars and practitioners did not predict the possibility of this negative empowerment that seems fueled by a politically driven, conspiracy and grievance laden infodemic, which seeks to undermine public health experts and institutions, and even sacrifice the public's health for political gain.

4. Outcomes of politicization and negative empowerment

"Without health literacy, medicine fails, public health fails, and people pay the cost for those failures with their lives. This could not be truer than in the emergence of new diseases around the world, and, in particular, the COVID-19 pandemic" [28].

Public health efforts during the pandemic achieved some success. About 272 million Americans obtained the primary series of the vaccine [6]. More than 80 percent of the U.S. population received at least one dose, preventing an estimated 18.5 million hospitalizations and 3.2 million deaths, and saving \$1.5 trillion [29]. However, roughly 40 percent of deaths due to COVID-19 in the U.S. could have been prevented if Americans followed recommended public health measures [30]. Cornell University researchers found media mentions of former President Trump within the context of COVID-19 misinformation comprised 37.9% of the infodemic [21].

In March 2023, the infodemic continues to undermine public health efforts. Only 16.3 percent of those eligible have obtained boosters; and 300–500 Americans die from COVID every day [6–8].

New variants continue to arise [31]. Resistance to annual vaccines for COVID has extended to other diseases, schools and childhood vaccination requirements [32,33]. Legislation has required the U.S. Secretary of Defense to rescind its vaccination mandate [34]. As a result of vaccinations missed during the pandemic and increasing vaccine hesitancy, the U.S. has seen an increase in measles cases in 2020, 2021 and 2022, all among children who were not fully vaccinated, with cases or outbreaks in eight states [6].

Acceptance of unproven, potentially dangerous, alternative COVID treatments (horse wormer, malaria medications, ingested bleach, light in the body), and claims of natural immunity and religious protections have emerged and continue to garner support [35,36].

Recently, the U.S. House Oversight and Accountability Committee formed a Select Subcommittee on the Coronavirus Pandemic to investigate the origins of COVID-19 [37]. Claims that the COVID vaccines contain formaldehyde or tracking devices, sterilize women and alter DNA are among the disinformation that continues to spread [38,39].

The state of Montana has banned vaccine and mask mandates and Florida is considering a similar bill [40,41]. Idaho Republican legislators have introduced a bill making it a felony to provide a COVID injection and to outlaw vaccine and mask mandates in schools and workplaces [42]. A lawmaker in Montana recently proposed a bill banning COVID-vaccinated people from donating blood, thus making it a crime to donate blood containing "novel mRNA or DNA pharmaceutical biotechnologies" [43]. The recently reintroduced *Health Freedom for All Act* would disallow any future Occupational Safety and Health Administration (OSHA) required mandate for an employer-based COVID-19 vaccine [44].

Further, conservative supporters of the former President in the U.S. House of Representatives are leading efforts to control the infectious disease research agenda and challenge funding for the National Institutes of Health's (NIH) research on vaccines [45]. Without evidence, proponents claim that improper oversight by NIH, particularly Dr. Fauci, led to the pandemic and that NIH has awarded U.S. taxpayer dollars to China and other communist countries [46]. Another bill under consideration would ban the U.S. Centers for Disease Controls (CDC) and NIH from funding laboratory research in China and other countries, ending any existing or future collaboration [47,48].

5. Why the infodemic worked and keeps working

As long as health literacy is limited to healthcare settings and patients are defined by their disease; as long the demands and challenges of their everyday lives are ignored as irrelevant, and their non-clinical sources of information are disregarded as unreliable, patients will remain dependent on clinicians. Their power will be limited to following instructions. Research findings will remain largely uninformative [3].

In many ways, the COVID-19 infodemic fits the model of an ideal public health campaign. It is a multipronged national level approach launched by the (now former) President of the U.S. and carried on by supporters in Congress, and at multiple levels of government.

Messaging is tailored, amplified, and disseminated rapidly through social media, along with selected news outlets favored by target audiences, advocates in state and local government, and grass roots networks of local influencers. Citizens are taking recommended actions related to personal health and participation in public health policy.

The COVID infodemic exploits an environment of fear, confusion, and grievance [12]. The infodemic also exploits the following vulnerabilities within the U.S.' public health and healthcare systems:

- Longstanding policy inattention to prevention. Treatment of disease is profitable, while prevention is seen as a cost with an uncertain return on investment. Citizens have been led to think prevention is unnecessary in the most advanced medical system in the world. Public health budgets have been declining since 2000; by 2020, pre-pandemic, just 3 percent of \$3.6 trillion U.S. healthcare dollars went to public health and prevention [49].
- Vulnerable public health infrastructure. "Under-resourced, understaffed, and overburdened health agencies responded to a major pandemic with inadequate systems, and the country's longstanding failure to invest in disease prevention, address the root causes of poor health, and promote health equity made the nation less resilient" [49].
- Dismissal of the Internet, social media, and non-medical influencers and commentators as sources of health information and pandemic response. With physicians perceived to be the sole source of reliable health and medical information; distrust, lack of access, and absence of effective public rebuttal leave citizens vulnerable to disinformation. This perception of doctors as keepers of knowledge is exploited by advocates with medical credentials and pseudo-scientists who use scientific-sounding language and selective reporting and interpretation of research findings to endorse false claims.
- Excess attention to functional literacy and information architecture juxtaposed by inattention to critical health literacy and empowerment, and components of the expanded model of health literacy: media literacy, science literacy, civic and cultural literacy [2].
- Low science and health literacy among many political leaders, commentators and some journalists allow advocates to reframe scientific uncertainty and the evolutionary nature of scientific knowledge as incompetence, lying, conspiracy, or malicious intent, thereby casting doubt to distract from poor optics, political liabilities, and a failed response.
- Failure to anticipate the infodemic. Although public health measures have been entangled with the far-right agenda for more than 140 years, practitioners and scholars never envisioned that government elected officials at the highest levels would attempt to hold on to power by intentionally damaging the nation's health during a pandemic through an intense disinformation campaign gone viral [16].
- Public health education, health promotion, and health literacy program planning that has not considered
 movements that might intentionally increase confusion instead of clarity, build on individual grievance
 instead of social responsibility, intentionally reduce health literacy, and sacrifice the nation's health for
 political gain.

6. What to do now

"The problem isn't a lack of facts. It's about what sources people trust" [38].

The following steps taken now, while the pandemic is contained, could promote health literacy, establish a presence and credibility of medical and public health authorities, buttress efforts to debunk conspiracies, and facilitate a ready response to crisis.

- Refocus health literacy research and practice more broadly to address critical health literacy, media literacy, science literacy, civic and cultural literacy.
- Incorporate measures of scientific quality for health reports in the lay press [50,51]. In keeping with critical health literacy, emphasize media literacy that differentiates between valid news reporting, which provides interpretation of evidence, explanation, and context, and commentary, which expresses opinions about issues of public interest [52].
- Collaborate across health and medical silos and sectors to grow a counter offensive promoting vaccines, masks, and the authority of the Centers for Disease Control and Prevention's recommendations. With the emerging field of infodemiology, build a foundation for effective public health response to the next pandemic.
- Develop consistent messaging adapted for multiple audiences broadcast widely and frequently in the absence of a crisis.
- Clarify the role of physicians. Physicians can play a significant role in promoting individuals' health literacy and empowerment by building trusting relationships with patients that allow correction of mistaken beliefs [26]. However, physicians cannot be the sole or primary promoters of health literacy nor the first line of defense against disinformation and manipulation. The COVID-19 infodemic foments distrust of the medical establishment as well as public health authorities. Further, building trust takes more time and interaction than is typically available in episodic clinical visits. Millions also lack access to a personal physician, particularly during a pandemic.
- Establish purposeful and focused workforce succession planning with public health and medical training programs that include historical politicization of public health and distrust of healthcare. Health crisis planning should anticipate public resistance. Put the 'P' back in the name and purpose of the CDC.
- Enact policies to bolster the U.S. public health system by:
 - (a) Substantially increasing core funding to strengthen public health's infrastructure and workforce. Prioritize funding for populations at high risk from disease and disinformation due to the impact of racism, poverty, systemic discrimination, and disinvestment.
 - (b) Improving public health emergency preparedness and response.
 - (c) Safeguarding and improving U.S. residents' health by investing in disease prevention.
 - (d) Addressing the social determinants of health broadly and inclusively in early public school and medical school training [49].
- Take extreme factions seriously. While it is unlikely that anti-public health bills under consideration will be enacted at the federal level during the Biden administration, they are already being enacted by some states. Purveyors of the present and future infodemics must not be dismissed; they lay out an agenda to control and weaponize public health institutions and undermine government response to health crises.

7. Summary

"Those that fail to learn from history are doomed to repeat it." - Winston Churchill

The COVID-19 pandemic increased health literacy demands for U.S. purveyors and consumers of health and medical information and presented opportunities to promote health literacy and empowerment.

Public health efforts were generally effective. That most Americans adopted preventive measures suggests an overall increase in health literacy around infectious disease and empowerment for personal and community benefit. Improvements occurred despite the introduction of many new terms and concepts, evolving scientific underpinnings, and inconsistent public health messaging.

However, a nationwide infodemic fueled by some politicians and health freedom activists empowered millions of Americans with a deluge of disinformation that buried the facts, challenged even those with advanced health literacy skills, and promoted over-confident self-management of COVID. Outcomes demonstrate the risks of empowerment in the absence of critical health literacy.

The COVID infodemic succeeded in undermining public health institutions and authorities, sowing doubt and distrust of government, and fear of vaccination. It enflamed grievances old and new to achieve surprising levels of participation in social and political action around public health policy.

The negative empowerment of segments of the U.S. population reveals the extent of inattention to: critical health literacy among citizens, some politicians and information providers; prevention and public health infrastructures; social media platforms and other non-medical information sources; and historical resistance to public health efforts.

Effective preparation for expected future national and global public health crises will begin with health literacy scholars and practitioners embracing the complexity of unknowns, data lags, and public health policies, while anticipating a well-established and networked resistance to planned government response. A flexible, collaborative, creative, forward-thinking mindset and a multi-faceted strategic approach focused on critical health literacy can empower citizens to better assess and apply information to protect and promote individual and public health.

In short, as Andrew Pleasant posted on his Twitter account in 2011: "Enjoy the practical wisdom of daily life. Promote truth & honesty. Denounce bullies & liars. That's about it".

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