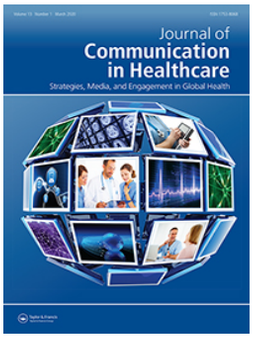

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LETTERS: VIEWPOINTS ON CURRENT ISSUES

Health literacy and early insights during a pandemic

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ABSTRACT

Health communicators can draw some early lessons from the first five to six months of the worldwide experience with the Coronavirus Disease 2019. While it is critically important to apply known efficacious principles of communication strategies, we would do well to imbue our efforts with insights from health literacy studies. We know from national and international assessments that a significant proportion of adults in most industrialized nations have limited literacy and numeracy skills and face difficulty using commonly available materials to accomplish everyday tasks with accuracy and consistency. We must be certain to make information more accessible by being attentive to tone and voice, organization of information, vocabulary, numbers, data presentations – in our talks, writings, and postings. We need to apply rigor to the development of written, spoken, and displayed information and be certain to use available tools to develop, assess, pilot, and re-formulate health messages and materials - to help the public gain access to needed insights, developments, instructions, and actions. The health literacy lens supports a focus on the characteristics of health communications that facilitate or impede access to information, comprehension, and action. We know too that we must make critical information more widely available - considering that the most vulnerable amongst us may have limited literacy skills, have access to scarce resources, and face higher exposure. Health literacy insights can support strategies to broaden the reach of health information and contribute to efforts to mitigate the ravages of disparities.

KEYWORDS

Health literacy; pandemic; coronavirus; COVID-19

An enormous amount of Coronavirus Disease 2019 (COVID-19) information – including daily reports from affected countries, charts of numbers of deaths, discussions of deficiencies in needed equipment, critical action alerts, as well as the multiple stories of affected communities, families, and individuals – is flowing through media channels. We know that openness and shared information builds trust between the members of the public and those who generate and disseminate knowledge – including scientists, health researchers, policy makers, health care practitioners, health writers, publishers, and journalists. As a result, communication is a primary public health strategy – to help people keep abreast of new developments, make informed decisions for themselves, their families, and their communities, and be prepared to take action, especially during times of natural disasters and emergencies.

Yet, complex or discordant information can raise problematic issues and engender confusion and chaos. Anticipating and planning for effective communication in disaster and emergency conditions is a best practice and would have helped the current response. Our purpose is not to critique, however, but to show how health literacy insights, combined with long standing risk communication strategies, will support efforts to communicate information both in times of calm as well as in times of crisis.

Health literacy concerns

Marginalized people in all societies are clearly more vulnerable to COVID-19 in multiple ways: more likely to be living in compromised or hazardous environments, dealing with a variety of problematic health issues, facing economic hardships, and engaged in occupations that put them at further risk. It was clear from the start of the pandemic that elders are at higher risk to succumb to COVID-19. Furthermore, recent observations indicate that death rates are higher among socially vulnerable population groups – among minority groups and those who are poor. We have long known from international adult literacy surveys that we find lower literacy skills among elders, those who carry minority status in any society, those who live in under-resourced areas, and among those who live in poverty.

Surely, special efforts must be made to communicate plainly to all and with urgency to the most vulnerable. In addition, we must be cautious, in our technologically savvy societies that allow many to work from home, that we do not rely solely on communication channels that are available only to the privileged. We must find ways to make information and resources readily available to those with and those without internet or WIFI, to those who have a doctor

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or medical team they can reach out to and those who do not, to those who can shelter in safe places and those who cannot. World-wide efforts have included the use of public postings, handouts, and mailings, as well as information delivery through the spoken word, visuals and videos, the Internet, as well as through local and national newsprint, radio and TV. We are uncertain, thus far, about the application of focused dissemination strategies for making key information available to the most vulnerable groups – but must certainly advocate for such efforts.

At the same time, we note that the health literacy emphasis on clear information remains true for communication with all members of our society. We can no longer think of health literacy as a focus on those with low or limited health literacy or as a focus on the skills and abilities of individuals. Literacy, and health literacy, is always an interaction: a rich interplay of the skills of the public and the demands of texts, of the listening skills of people and the communication skills of speakers, and of the needs and desires of people to engage and the features of health systems that support or inhibit access. We improve health literacy by improving either or both sides of the equation. In the short term, we must emphasize improvements in our communication efforts [1].

We make a distinction between information that is available and information that is accessible. Available information that is not clear to the wide variety of key players and the lay public stymies the flow of knowledge and inhibits action. A health literacy lens can enrich the findings and practice guidelines generated by health communication studies and help make readily available health information – presented through multiple media, more accessible and usable. We can make improvements through attention to rigor, clarity, numeracy, and articulated action steps. As a result, we are better able to help people stay informed, confident, and prepared to act.

Rigor

Health literacy research over the past two decades has indicated a strong mismatch between the known skills of the public and the complexity and difficulty of health and science information. Myriad studies have indicated that health information across a variety of subjects is jargon filled, poorly organized, and not accessible to the average high school graduate. The development of health information does not seem to be treated with the same respect as is the design of other health products that are rigorously developed, pilot tested, revised, and assessed again before dissemination. More attention must be given to rigor in the planning, shaping, and delivery of health information – whether it is to be disseminated in print, through dialogue or public speech, online, via the airwaves, through visuals, or via mobile devices.

Testing during an emergency response can be challenging, but it can be done quickly if needed, drawing on currently available information about the public in general or about population segments, and then via small-scale pilot testing. For example, Centers for Disease Control and Prevention (CDC) teams conducted real-time formative research in the U.S. Virgin Islands and Puerto Rico during the 2016–2017 Zika virus outbreak. Team members were looking to understand information gaps, message effects, and health behaviors that could modify future health messages, materials, and programs. The results informed the local health departments' communication, education, and engagement work to promote the recommended health behaviors [2, 3]. Another approach for U. S. practitioners can be found in the Health Information National Trends Survey (HINTS) and its freely available data on different groups' preferred information channels and sources [4].The HINTS data can be supplemented with local consultations with organizations that serve an intended population segment. As part of a trusted partnership arrangement, an organization can ask a small number of its clients or members to volunteer to provide a quick review. Of course, establishing ongoing rigorous programs of formative research and practicing the use of guidelines constitute key elements of communication preparedness.

Clarity

Those of us communicating health and science must take responsibility for easing comprehension and facilitating the use of information. Ease of reading, listening, and comprehending is shaped by a variety of factors including an evident purpose, a meaningful context, a friendly and conversational tone, a logical chunking of like information, and a familiar and appropriate use of language. Of critical importance is that meaningful information can be readily recognized and that action steps can be taken.

Assessments of the match between the known reading skills of the public and the demand of any text (spoken, written, or illustrated) include a focus on vocabulary. Vocabulary is just one indication of the complexity and difficulty of a text. Communication messages and materials related to COVID-19 have introduced unusual vocabulary and phrases into common speech over the past several months, such as 'containment', 'mitigation', or 'flattening the curve'. Early use has almost uniformly been accompanied by definitions, examples, and illustrations. This is required when any new word, phrase, or concept is introduced. Over a short time period, these previously rare words have become commonly understood. At the same time, many mundane or common words have proven

problematic, in part because they are taken for granted and not defined in context. For example, the very valuable first-person accounts highlighted in the news include both people diagnosed with COVID-19 who seem very ill as well as those with the illness who seem functional. Yet, few reports have focused on what individuals can expect if they become ill and how to judge whether their case is mild, moderate, or severe (a cause for immediate action). Descriptive words such as 'mild' or 'moderate' are imprecise and, when offered without explanation, leave the audience unsure what to expect and unclear what type of action is needed.

Freely available health literacy assessment tools offer measures of key components that can be used to test as well as to develop health messages and materials. The CDC Clear Communication Index [5], one such tool, highlights several key elements of what an efficacious 'message' should include to ease the burden on audiences who need to grasp the core content, assess the risks, and take action. These include a clearly stated main message, action steps, explanations of risk, attention to the organization of ideas and information, and consistent and logical use of numbers, numeric concepts, and data displays. Assessment tools, critically important for rigorous review, re-writes, and re-designs should help guide message development.

Numeracy

Attention to the use of numbers is critical as well. In light of the current pandemic, numbers can offer people a grounding in events, provide them with the means of comparison, or alert them to needed action. However, all of the national and international literacy surveys have indicated that numeracy skills are problematic for a large proportion of adults in almost all industrialized nations. For some, numbers will shape perceptions and carry persuasive power. For others, numbers – especially in the form of fractions or percentages or with decimal points, will surely sow confusion. For example, some audiences might have seen the case counts and deaths related to COVID-19 in their area or country and concluded that the numbers indicate a need for immediate protective actions. Others, finding no denominator for case counts, question what the numbers mean. Still others, recalling how some political leaders or pundits compared the coronavirus numbers to the seasonal flu numbers, might conclude that action could be delayed.

There are multiple lessons to be learned from health literacy studies. Ancker and Kaufman highlight important design considerations for the display of health-related information [6]. Apter and colleagues provide a hierarchy of difficulty, noting for example, that whole numbers are easier to grasp than are fractions or numbers with decimals,and stress the importance of doing any needed calculations for the user [7]. In general, the presentation of scientific and medical data has not yet been given the strategic consideration needed. Analyses of numeracy demands during the pandemic will surely be forthcoming. For now, we must, as Zikmund-Fisher cautions, be mindful of the benefits and downsides of numbers, accompany numbers with explanations, and present data in a meaningful context [8]. What it is people are expected to do with the numbers must be considered and overtly addressed.

Numeracy also includes attention to mathematical concepts such as risk. Risk is a very sophisticated math concept that has proven problematic to define. Still, presentation of risk is often considered as a decision tool and thought of as a motivation for action. Practitioners have grappled with the use of similes, metaphors, or case examples. During the current pandemic we have noted that risk has been communicated in multiple ways. News photos of young people at the beach, of community gatherings, or of politicians at meetings providea jarring contrast to discussions of risk and a declaration of 'war' on the virus. These competing data and visuals – all representing notions of concern,may have left people unclear about the nature of the risk for themselves and others.

Health communicators must balance keeping informational materials easy to understand with the critical task of enhancing public understanding of health risks. One example of these trade-offs is educational videos or animations about COVID-19. Many are brief (1-2 min) and provide basic education about the coronavirus and protective behaviors. Explaining the nature of the risk – who is at risk, why, and how the protective behaviors relate to different risk profiles – has proven more challenging. Zikmund-Fisher persuasively argues for and illustrates the importance of providing relevant contextual information and 'information evaluability' along with numbers and numeric concepts [8].

Action

Health literacy assessment tools have consistently included positive points for providing action steps in all health messages. Behavior change is currently being spurred by consensus messaging and the 'new normal' is bringing about changes in public behaviors, increased appreciation for global action, and recognition of the need for public health preparedness. From the beginning of the COVID-19 response, social distancing and handwashing have been key recommended actions. Handwashing messaging in particular is experiencing something akin to star status as videos, songs, infographics, and more not only admonish people to wash their hands but also show

them the nuances of doing so. For another example, use of masks has not yet been commonly adopted in all parts of the affected world. In an effort to support normative change in the U.S., the current U.S. Surgeon General developed a YouTube video showing how to make a cloth mask from available materials and rubber bands. Clear and consistent actionable messages must continue to be highlighted. We must acknowledge that action options for those not privileged with access to water, soap, or materials for masks have not yet been developed, disseminated, or communicated.

Seeds of needed change are also being planted as new discussions focus on inequities.

Conclusions

The COVID-19 pandemic is only months old and what we know about the virus, the disease it causes, efficacious actions, evidence-based medicines, and how to best communicate the risks and protective actions will evolve. A health literacy lens for COVID-19 communication enables us to acknowledge the public's documented literacy related abilities and deficits but it also turns our attention to needed improvements in the skills of those who craft and deliver messages and recommendations. We urge health communicators and educators to take the following steps:

- Commit to rigor and find ways to test COVID-19 messages and information before releasing them to the public.
- Apply documented organizational and stylist approaches that ease comprehension and be attentive to words and numbers.
- Use everyday words with helpful explanations for any new context. Define all unusual words and provide relatable examples.
- Explain and provide a meaningful context for numbers. Link interpretation to recommended action.
- Highlight protective health behaviors and include necessary directions.

Health literacy findings have been informing strategies in health care and public health with the goal of making health information clear so that all members of the public can access needed health information for mundane and critical decisions. A health literacy lens turns our attention to the skills and abilities of those of us who shape health related messages and data, to the characteristics of health materials that facilitate or impede comprehension, and to those aspects of our health and health care systems that erect barriers to information, services, and care [1]. This lens can support efforts to mitigate the ravages of disparities and inequities. ~~

Rima E. Rudd and Cynthia E. Baur, April 13, 2020

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