

Cinnamon Rolls Cure Diabetes: Deception, Disinformation and Controversy in Online Health Information

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The title is an example of the outrageous health claims that are increasingly commonplace in our electronic ecosystem. According to a recent Pew Research Center report, 62% of adults in the U.S. get their news via social media(1). Although Facebook has recently made an effort to reduce sources of misinformation (that appear as unsolicited content), these information sources are not typically vetted, checked for accuracy or monitored in any way(2). Evidence suggests that high school and college students are easily deceived by fake news while perusing through social media sites(3) Many sites prey on vulnerable populations who may be receptive to a quick and easy cure or an alternative to medical establishment recommendations. For example, a newspaper in the UK commissioned a study that found that the majority of the most-shared articles on Facebook in 2016 with the word “cancer” in the headline included claims discredited by health authorities (4). The epidemic of fake or controversial health news presents formidable challenges as well as interesting research opportunities to the consumer health informatics community. The four panelists are collaborators in a nascent research program that focuses on issues pertaining to the assessment of quality of online health information from “unconventional sources,” or sources that make claims unsupported by the medical establishment. Problematic health news reflects a continuum from deliberately deceitful information with the intent to promote specious products to sites that advocate for or against a particular health practice like the “anti-vaxxers” movement. The panelists will draw on related studies addressing challenges pertaining to healthcare practices and the role of information technology in both exacerbating and addressing this problem. We anticipate that this will be a controversial subject and plan to devote about 1/4 of the session to question and answers with the audience.

David R. Kaufman, PhD, Reconceptualizing eHealth Literacy

Dave Kaufman, panel moderator, will explore efforts to extend the eHealth literacy framework to the challenges presented by “health news”. eHealth literacy names a set of skills and knowledge that are essential for productive interactions with technology-based health tools(5). It also identifies a burgeoning area of research focused on understanding the ways in consumers or patients can negotiate technology-mediated tasks. There have been several efforts to develop evaluation methods(5, 6). The approach has been particularly useful in examining the challenges imposed by information-seeking tasks. However, it has not been extended to social media. The vehicles for disseminating such health news differ in important respects. While it is possible to access these sources through a Google search, the sites are typically available as clickbait and may be appended to reputable sites such as the New York Times. In addition, much of the information may be conveyed through videos that bear close resemblance to infomercials.

Catherine Arnott Smith, PhD, The Discerning Health Consumer

Catherine Arnott Smith will discuss the promise and limitations of research using DISCERN, the widely used set of quality criteria developed for consumer health information on treatment choices. The DISCERN instrument was developed as a collaboration between the National Health Service and the British Library. DISCERN’s creators designed it to support screening by health information providers, serve as a checklist for content creators and a training tool for healthcare professionals, and most important, as a decision support for consumers who want to know more about a treatment they are using(7, 8) DISCERN was born of work done by stakeholders from across healthcare: generalist and specialist physicians, health communications specialists, self-help patient group representatives, medical publishers and journalists, and health services researchers focusing on trials. DISCERN is a free tool intended to be consumer- and patient-facing, although studies have actually found that DISCERN rankings are similar when done by healthcare professionals. It is frustrating that this validated and well-studied instrument is not better known in 2017 by both physicians and consumers. However, DISCERN’s focus on decision support for evaluating treatments gives it a particular focus and makes it inappropriate for certain uses. The presentation will explore the ways in which DISCERN can be leveraged and extended for the complexities of evaluating health information via social media.

Alla Keselman, PhD, Evaluating Argument Structure and Scientific Content of Unconventional Information Sources
Alla Keselman will discuss the role of background knowledge in consumers' ability to evaluate health information. She will also present an analysis of content claims and other characteristics of unconventional health websites. Evaluating claims of treatment effectiveness requires lay individuals to deal with complex biomedical information. Our previous research suggests that without adequate knowledge, individuals are easily swayed into erroneous health beliefs. For example, adolescents who do not understand the nature of viruses may readily accept that HIV can be "expelled" from human body through urine and sweat(9). Unfortunately, acceptance of prevalent, but erroneous health beliefs (e.g., vitamin C prevents common colds) is common even among individuals who had studied biology in high school and college(10). For the current project, we augmented existing health information evaluation instruments such as DISCERN with qualitative criteria analyzing argument structure and scientific content of medical claims made by unconventional information sources. We developed a scheme for evaluating both informational features and scientific concepts of health information sites. In this talk, Dr. Keselman will present results of a study applying the coding scheme to a Google search results to the query "diabetes, reversal, natural". She will also discuss the role that science education and consumer health informatics can play in empowering lay health information seekers.

Anita Murcko, MD, FACP, Reconciling Clinical Perspectives on Health "News" Management

Anita Murcko will discuss some of the challenges that confront physicians and other health care professionals as they help patients negotiate the ever-changing consumer health space. She will also discuss the results of an ongoing study in which undergraduates are asked to render a series of judgments about health websites (legitimate and otherwise) with and without evaluation criteria. Patients are increasingly expected to assume a greater role in managing their own health, however, many feel uncomfortable about how and where to find suitable, actionable information. Web health resources are vast, including those pushed through social media to health consumers and patients. These sites commonly promote products lacking evidence of efficacy. This behavior is frequently observed and has particular implications for people with low health literacy and those who are desperate for a quick solution to a health problem. Specific examples will be examined.

Panel Discussion Objectives and Expectations

The learning objectives include—to: **(1)** Characterize the dimensions of the problem confronting health consumers and patients in evaluating the quality of online health information; **(2)** Describe the evolving criteria and methods necessary to render judgments about the value and soundness of information resources; **(3)** Discuss the role that science education and consumer health informatics can play in empowering lay health information seekers; **(4)** recognize the challenges that physicians are confronted with in helping patients negotiate the morass of online health information; **(5)** Engage in a discussion exploring the viability of various technological, cognitive, social and education solutions to this vexing problem.

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Panelists Biographies

David Kaufman is trained as a cognitive psychologist with a PhD in educational psychology. He is currently an Associate Professor in the Department of Biomedical Informatics at Arizona State University and Research Affiliate at the Mayo Clinic. He has worked in the area of human-computer interaction and human factors for the last 20 years. He has extensive experience conducting cognitive research in relation to informatics initiatives and evaluating a wide range of health information technologies developed for clinicians, patients and health consumers. He has also engaged in research with patient and consumer populations of varying levels of literacy. A primary focus of his research has been on eHealth literacy, a set of skills and knowledge that are essential for productive interactions with technology-based health tools. eHealth tools are rapidly being developed to engage people in managing their own health care, to facilitate communication with providers and social networks, meeting their informational needs, making knowledgeable health decisions, using patient education resources, and promoting healthy lifestyles. Since 1994, he has been involved in several human computer interaction projects pertaining to the evaluation of electronic health records, computer-provider order entry systems, language learning systems for medical professionals and a large-scale telemedicine system for patients with diabetes. Dr. Kaufman's current work in clinical informatics is on EHR-mediated workflow in surgical settings.

Catherine Arnott Smith, is an Associate Professor at the Information School and a Discovery Fellow attached to the Wisconsin Institute for Discovery, University of Wisconsin-Madison. She obtained a master's degree in Information Science/Medical Informatics and a doctorate in Library & Information Science/Medical Informatics as a Medical Informatics Trainee at the Center (now Department) of Biomedical Informatics at the University of Pittsburgh. Her research interests center on health information provision "in the wild" outside of clinical settings.

Alla Keselman is a Senior Social Science Analyst in the Division of Specialized Information Services, National Library of Medicine. Her research interests include lay understanding of health concepts, consumer health informatics, health information provision outside healthcare, and the relationship between health and science education. Dr. Keselman has published extensively in informatics, information science and science education literature. Much of her work focuses on lay misconceptions about health and disease and the barrier this presents to information seeking. She is a co-chair of Science|Environment|Health Special Interest Group of European Science Education Research Association that promotes integrating biology of health and disease into the school science classroom, asserting significant benefit to daily health functioning, informed citizenship, and science education. She also led the development of a number of National Library of Medicine websites presenting genetics and environmental health information to the general public. She holds a doctorate in human cognition and learning and a Master's in biomedical informatics from Columbia University. Dr. Keselman is co-editor with Catherine Arnott Smith of [Meeting Health Information Needs Outside of Healthcare: Opportunities and Challenges](#) about the ways consumers seek, find, and process health information. She was the recipient of the NLM Regents Award for Scholarship.

Anita C. Murcko, a board certified internist, is a Clinical Associate Professor at the Arizona State University, Department of Biomedical Informatics, faculty with the University of Arizona, College of Pharmacy, a Mayo Clinic research associate and president and CEO of her e-health consultancy. She has nearly 30 years of healthcare experience, including over 20 years practicing internal medicine and over 15 years as a medical executive specializing in quality improvement and healthcare systems redesign in the public and private sectors. Dr. Murcko served Arizona's Medicaid agency, AHCCCS (AZ Health Care Cost Containment System) as the medical director and the Agency's first director of clinical informatics and provider adoption where she provided clinical leadership for Arizona's first health information exchange (known as the Arizona Medical Information Exchange (AMIE)) and the Purchasing & Assistance Collaborative for Electronic Health Records (PACeHR.) She was previously the Chief Medical Officer for Health Services Advisory Group (HSAG), a national healthcare quality-improvement organization (QIO) serving Medicare, Medicaid and private clients. Dr. Murcko is a recent recipient of the American College of Physicians (ACP) Laureate and Leadership Awards.

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