The role and impact of health literacy on peer-to-peer health communication

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Abstract. This chapter explores the impact and role of health literacy in peer-to-peer health communication contexts, such as social media platforms and online patient support groups. The chapter contends that health literacy efforts of researchers, health care providers, and public health practitioners will need to include innovative strategies to help consumers critically evaluate and appropriately utilize the health information found in online communities.

The chapter first discusses the rise of peer-to-peer sharing of health information and accompanying health literacy concerns. Next, a series of case studies are presented that illustrate the potential role of health literacy in three different online settings: clinical trial patient support networks, social media channels, and personal blogs. The chapter then explores common themes highlighted in these examples and discusses the range of health literacy benefits and pitfalls that accompany the use of these channels for health information.

Finally, the chapter explores existing individual-level and system-level health literacy initiatives for peer-to-peer health communication and suggests opportunities for future work in this area. Such efforts to address and improve health literacy can help individuals and communities successfully navigate online platforms where peer-to-peer health information is exchanged.

Keywords: Health literacy, peer-to-peer health communication, social media, patient support groups

1. Introduction

In the years between 2014–2017, hundreds of Tweets appeared using the hashtag "#VaccinateUS". While most vaccination hashtags explicitly take a point of view (e.g., #vaxwithme, #CDCwhistleblower), Tweets using the #VaccinateUS hashtag curiously promoted both anti and pro-vaccine messages. The tweets included:

"At first our government creates diseases then it creates #vaccines. what's next?! #VaccinateUS"

"Do you still treat your kids with leaves? No? And why don't you #vaccinate them? Its medicine! #VaccinateUS"

"Apparently only the elite get 'clean' #vaccines. And what do we, normal ppl, get?! #VaccinateUS"

"#vaccines cause autism—Bye, you are not my friend anymore. And try to think with your brain next #VaccinateUS"

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An analysis of this hashtag revealed the "VaccinateUS" was likely a hashtag created by Russian "troll" accounts, which used both pro and anti-vaccine messages with the intention to sow discord about vaccination in the U.S. [1]. Messages employing this hashtag tried to frame the vaccine debate using polarizing health themes, such as conspiracy theories, attempted to revitalize a debunked vaccine-autism link, and promoted controversial mandatory vaccinations.

This use of trolls and malicious social media messaging techniques provides an example of an increasingly sophisticated, opaque, and complex online health information ecosystem that today's health consumers must navigate. Popular social media platforms, such as Twitter, Facebook, and Pinterest, are common channels through which individuals may be exposed to and influenced by peer-provided (mis)information about health topics online, although exposure occurs on a variety of other online platforms as well. From online patient networks and advocacy boards, to user-generated content on YouTube and Instagram, individuals find many online avenues to share information and connect with one another about health. However, because the information being shared is typically provided by peers rather than health care professionals, it has often not been vetted or verified, and it can be difficult to identify the original source of information. Given the prevalence of online health information searching and the amount of medical and scientific information that individuals may be exposed to on peer-to-peer platforms, it is vital to study how individuals process and evaluate this information. As health information becomes increasingly available and complex (e.g., genetic information, personalized medicine), the need for consumers to critically evaluate information found on these platforms and make health-related decisions based on the provided information will intensify in the future.

Adding to this complexity, research suggests a substantial proportion of health-related messages on peer-to-peer platforms contain misinformation. For example, a content analysis of prostate cancer videos on YouTube reported 77% of the videos and comments contained biased or false information [2]. Similarly, a content analysis of $n = 800$ vaccine-related posts on Pinterest revealed that 21.5% of posts mentioned a conspiracy perpetrated by either the government or the pharmaceutical industry [3]. Alarmingly, the most popular and frequently shared posts and videos are often the ones that contain misinformation [2,4]. This suggests the health literacy efforts of researchers, health care providers, and public health practitioners also will need to include innovative strategies to help consumers successfully identify and distinguish between evidence-based and non-evidence-based information.

The first step to help individuals navigate this complex online environment is to consider the role of health literacy in peer-to-peer online health communication. A better of understanding an individuals' beliefs, abilities, and perceived efficacy to navigate online health (mis)information provides insights into strategies to help consumers with different health literacy levels discern the meaning and usefulness of health information discovered on peer-to-peer platforms. Appreciating the role of health literacy in this context also may facilitate the design and development of more effective health communication interventions designed for and delivered through peer-to-peer platforms.

In this chapter, the authors discuss the important role health literacy plays in online peer-to-peer communication. We first define and operationalize online peer-to-peer communication and health literacy. Next, the authors present three short case studies centered on cancer patient support networks, Instagram wellness accounts, and parenting blogs. These examples showcase the range of potential benefits and challenges of peer-to-peer communication about health, while highlighting health literacy as an important factor to consider within an increasingly complex mass communication context.

The authors contend that efforts to address and improve health literacy can help individuals and communities successfully navigate online platforms where peer-to-peer health information is exchanged. Such efforts can help inoculate individuals against health misinformation, facilitate decision-making among

those with limited health literacy, and increase the effectiveness of health communication campaigns and patient-provider communication by reducing the influence of health (mis)information.

2. The rise of peer-to-peer communication

The use of social media in the United States has increased from 5% in 2005 to 69% as of 2018 [5]. This remarkable growth may outpace health professionals' understanding of the way social media affects how individuals process, interact with, and act on the health information found on these platforms. A line of research spanning the past decade has attempted to address this phenomenon.

Much of the early work focused on understanding how individuals attempt to reconcile the health information they find online with offline sources. For example, some studies focused on how patients would discuss information found online during interactions with their healthcare providers [6]. Recent research examined the impact of mobile and social media on health communication across a variety of health topics, such as the impact of online support groups for breast cancer survivors, and the use of mHealth to deliver lifestyle interventions and social support for weight loss [7,8].

Peer-to-peer platforms have become rich sources of health information for patients and the public. In this chapter, the authors define peer-to-peer health information as user-generated health information that is created and shared with virtual communities or networks via computer-mediated technologies. Peer-to-peer platforms have benefited patients and public health researchers in many ways including: providing more opportunities for social support; increasing patient engagement and empowerment in health decision-making; facilitating adoption of recommended health behaviors; improving public health surveillance; and expanding the reach and cost-effectiveness of health promotion campaigns and interventions [9,10]. However, theoretical and empirical work points to pitfalls of online peer-to-peer health information sharing. These include increased distress and confusion in individuals when they receive conflicting information, and 'contaminating' research design (e.g., unblinding a randomized controlled clinical trial) [11]. Additionally, information sharing could lead to the deterioration of trust in government, scientists, and health care professionals when information found online contradicts a provider's recommendation or prescription. A recent study found a strong association between an individuals' efficacy related to searching for health information on-line and their trust in federal health agencies and national health organizations [12].

Among the most pressing concerns is the increased frequency of online peer-to-peer health information sharing may be associated with a concomitant increase in the volume of misinformation to which individuals may be exposed. Although definitions vary, in this chapter the authors define misinformation as a health-related claim of fact that, on its conventional interpretation, is currently false, because it: lacks scientific evidence; and/or is contrary to the accumulated scientific evidence; and/or is contrary to expert consensus, in whole or in part [13,14].

Some evidence suggests misinformation is processed and shared differently than evidence-based information on peer-to-peer platforms. For example, a recent study used rumor cascade methodology to better understand how misinformation and true information spread online [15]. In their analysis of 126,000 rumors spread by about three million people, the authors found that even after controlling for bot activity, "false news still spread farther, faster, deeper, and more broadly than the truth in all categories of information".

To maximize the benefits and minimize the potential harms of online peer-to-peer communication about health topics, individuals must be able to understand and critically evaluate the health information found on these platforms. There are diverse opportunities for public health practitioners, health care systems,

and industry partners to support individuals in developing these skills, which are necessary to consumers' meaningful engagement within the online health information environment.

2.1. Health literacy in the context of online peer-to-peer communication

Various well-cited definitions note health literacy is more than the ability to access or read health information. Rather, health literacy encompasses the capacity to comprehend the information provided and the ability to act on that information to improve health outcomes [16,17]. The rise of peer-to-peer platforms has helped limited literacy individuals overcome traditional barriers related to accessing health information [8]. However, in doing so, new health literacy challenges have been introduced, including the added challenge of evaluating peer-provided health information.

Previous research suggests health literacy plays a prominent role in how individuals discern and process health information found online. For example, one study found people with HIV who had lower health literacy were more likely than patients with high health literacy to give low quality ratings to a high-quality website and high-quality ratings to a low-quality website [18]. Other studies using education as a proxy for health literacy found educational level to be positively correlated with the number of successful information tasks participants completed (e.g., defining search options, evaluating information sources) and with their perceived self-efficacy in evaluating online health information [19,20].

Health literacy also has been associated with trust of online information and may help explain different levels of trust across peer-to-peer platforms. For example, one study found African Americans with lower health literacy were more likely to trust YouTube and Twitter for information, while African Americans with higher health literacy were more likely to trust online governmental and religious groups [21]. Moreover, the same study found that older adults who had low health literacy were more likely to trust information from Facebook but expressed lower trust in online support groups for health information.

3. Case studies of health literacy in peer-to-peer online networks

To illustrate the potential role of health literacy in online peer-to-peer contexts, the authors next turn to three case studies that showcase the range of online settings where health is discussed: clinical trial patient support networks; social media channels; and personal blogs. The authors deliberately provided a broad approach to consider a variety of online peer-to-peer networks where health information might be exchanged. Each case study explores some of the nuances and complexity of peer-to-peer health information sharing, which in aggregate, demonstrate the role of health literacy.

3.1. Case study 1: Online patient support groups and the angiosarcaoma project

Online patient support groups are one of the earliest forms of social media. In the early 1990s, patients, caregivers, and health consumers began to gather online to exchange information, offer personal illness stories and experiences, and provide and receive support from each other. Today, online patient support communities for conditions such as cancer are numerous. Online patient support communities transcend spatial boundaries and span organization-based communities, such as Cancer.net and the American Cancer Society's Cancer Survivors Network, and for-profit companies, such as PatientsLikeMe. Support communities can also take the form of member-only ("secret") groups on commercial platforms such as Facebook. Active online peer-to-peer networks focused on health issues are now an established channel of health communication.

For instance, a patient newly diagnosed with a rare disease may join an online peer community to hear about others' experiences living with the disease, find information about treatment options and side effects, seek social and emotional support from people that have had similar experiences, and even solicit and receive instrumental support (e.g., transportation to appointments). Moreover, such online communities, especially those with good administrative oversight, can provide unique opportunities for patients to engage in medical research and process disease-specific treatment information because these communities often become valued and trusted outlets for clinical trial information and relevant research.

In addition to peer-to-peer support for those with shared health challenges, online communities can serve to support cutting-edge medical research. One example of an online network that facilitates scientific research is the Angiosarcoma Project, founded by survivor, patient advocate, and scientist Dr. Corrie Painter [22]. This project has enabled the establishment of a large database of medical data (e.g., tumor samples and patient-reported outcomes data). The Angiosarcoma Project illustrates when thoughtfully created and consistently moderated, online communities help overcome information access barriers and facilitate patients' navigation and understanding of health challenges. In this way, peer-to-peer communication serves to overcome some health literacy challenges by making relevant information (e.g. treatment options, participation in research) much more accessible and personally salient.

Despite their potential benefits, online peer support communities also present new health literacy challenges, particularly as patients increasingly share complicated and personalized medical information and exchange medical opinions and advice. Trusted platforms for health information and disease-specific support may be even more vulnerable to the spread of misinformation about disease etiology and treatment options as well as the misinterpretation of scientific research results and clinical implications. For example, a patient financially compensated (i.e., "sponsored") by a pharmaceutical company might share information with her online peer support community about a drug purported to cure or benefit individuals with their shared health condition. Although the information may lack scientific support, peers within a network may view the information as credible since trust has been established within the community through shared experiences. While skillful online community administrators can help ensure group dynamics are supportive and helpful to community members, there also is a risk of creating an 'echo chamber'. The latter occurs when most members of the community express strong support for a particular treatment option (or doctor or health care setting) and drown out dissenting voices. The result may be a communication environment that feels unsafe, uncomfortable, or unsupportive for some individuals in the community who have different views. In such scenarios, an individual with limited health literacy may be more easily misguided by misinformation if he or she relies on advice from others as a way to cope with volumes of information perceived to be complex or confusing.

The Angiosarcaoma Project illustrates the importance of sustaining a 'health literate' online support community. Thanks to Dr. Painter's professional background, her team's attention to and careful moderation of online discussions, and the strong support of a research institute (Broad Institute), the information shared by peers about the disease remains evidence-based and community members feel empowered to participate and collectively contribute their clinical data to critical scientific endeavors. In turn, the Angiosarcaoma Project offers a model to create online environments that are conducive to the provision of evidence-based health information as well as improve individuals' understanding of their role in supporting others and contributing to research that may eventually alleviate suffering.

3.2. Case study 2: Lifestyle influencers on instagram

There is a an emerging group of popular influencers on Instagram who promote the idea of 'clean eating'. 'Clean eating', which focuses on the consumption of whole, minimally-processed foods, has the potential to benefit individuals by inspiring them to incorporate more fruits and vegetables into their diets and decrease the volume of processed foods they consume.

However, health providers are growing increasingly concerned about the potential harms of these accounts, suggesting they may be leading to increased distress and the development of eating disorders among followers [23]. For example, Orthorexia Nervosa (a new disordered eating pattern characterized by a fixation on eating only foods that are considered to be 'healthy' or 'pure') may be more prevalent because of the influence of digital media [24]. Persons who suffer from this disorder typically perceive foods that contain artificial ingredients or are grown by conventional means (e.g., with the use of pesticides) to be dangerous, and tend to avoid certain foods, such as those containing carbohydrates and fats.

A recent study suggests higher Instagram use is associated with greater Orthorexia Nervosa symptoms [23]. This is likely due to the influence of Instagram clean eating 'celebrities', who regularly dispense dietary advice to the hundreds of thousands of followers they have on this platform, despite typically having no formal training in health or nutrition. While some aspects of the diets these influencers promote may be consistent with scientific evidence (such as the emphasis on fresh produce), many of these accounts also implicitly or explicitly encourage the elimination of entire food groups, which runs counter to evidence-based nutrition guidance, and may lead to malnutrition and an unhealthy fixation on food.

Individuals who follow these Instagram accounts may have problems distinguishing between the scientifically accurate, legitimately helpful advice provided by these influencers and the more extreme, non-evidence-based views that are sometimes espoused in the same communities. The latter especially may be problematic for individuals with lower health literacy who may find the clear, simple, black-and-white messages about how to eat healthfully to be especially appealing. Acceptance of misinformation may be further enhanced by the attractive images that often accompany these Instagram posts (e.g., green smoothies, salad bowls), which may connote healthfulness even if the advocated pattern of eating is not healthy overall and the claims being made about specific ingredients are insufficiently evidence-based.

Indeed, many of the specific foods promoted by the "clean eating" movement, such as almond milk, or coconut oil, are not considered as especially healthy by certified nutritionists [25]. However, because influencers have a large following and an attractive appearance that reflects a healthful ideal, influencers are perceived as authorities on health. In one case, a popular Instagram influencer admitted that the raw vegan diet she was following - and promoting - was in fact making her very ill [25].

Furthermore, because most social media platforms are designed to continue exposing users to content they have liked previously, individuals who are interested in clean eating can get caught in an echo chamber where they are exposed to similar types of behaviors and information. This fosters a false impression about content veracity and normative behaviors [23]. Instagram's algorithms prioritize certain content and create echo chambers, making it less likely that people will be exposed to contradictory information, which might engender more self-reflection and personal research on the topic.

Yet, while popular 'wellness' accounts on Instagram are problematic in their current form, they demonstrate some potentially effective techniques that public health practitioners could adopt to promote healthy behaviors. For instance, advice from a personable, relatable, or even aspirational spokesperson may be better received than a factsheet from a faceless organization. Attractive, compelling imagery can make dry health information more engaging and motivational. People also appreciate practical tips and straightforward instructions they can act on compared to vague nutrition advice such as "choose a variety

of nutrient-dense foods" or recommendations that require math, such as "consume less than 10 percent of calories per day from added sugars" [26]. These strategies can help public health agencies make their health communication material more accessible for individuals at all health literacy levels.

3.3. Case study 3: The motherhood blogging community

Mothers who blog, sometimes called 'mommy bloggers', frequently post information about a variety of health topics pertaining to women and their family members [27]. As an example, The Motherhood (www.themotherhood.com) is a blogging community of mothers, many of whom were willing to facilitate the dissemination of evidence-based health information about environmental risks of breast cancer as part of an intervention study [28]. The bloggers worked with researchers to tailor blog posts that included evidence-based information about actionable steps that mothers and daughters can take to reduce the environmental risk of breast cancer. Often sharing personal family stories with family photos, their blogs may help people find, process, and understand scientifically complex environmental risk information by making it approachable. Their blog posts also inspired many mothers and daughters to discover and share health information on social media.

Findings from this research suggest peer-to-peer forums are a promising channel to make information more accessible and boost participant health literacy. By working collaboratively with mothers who blog, scientists can influence exposure to and diffusion of scientifically-informed health information in a way that is easier to process. Blog readers exposed to the researcher-adapted (www.bcerp.org) and blogger-tailored environmental breast cancer risk/prevention information were more satisfied with and influenced by the information when compared to readers who were not exposed (or did not recall seeing the messages).

Moreover, exposed blog readers were more likely to share the information with others in their social networks, especially their daughters [28]. Demonstrating the potential for improved health literacy among mothers and daughters, one blog reader said, "You read a lot of these white papers [educational handouts] and it's like, 'Look at all these words', and I don't know what they mean. So, when you have something that's like this [information translated for blogs], it's easy to digest. It's easier to recall when you need it for a conversation [with daughters]". Tailoring evidence-based health information for readers by providing personal accounts may increase the relevance of health-related information and comprehension, which improves the likelihood that readers will act on the guidance.

3.4. Case study discussion

Online peer-to-peer networks are increasingly used as a source of health information, and the three case studies suggest a range of benefits and pitfalls that accompany the use of these channels for health information. The common themes highlighted in these case studies include issues related to information quality and accuracy, the risks introduced by echo chambers, and the value of personal narratives and opinion leaders as possible sources to present information to individuals at all health literacy levels.

As discussed in the blogging case study, blogger-researcher partnerships and personal narratives can make peer-to-peer platforms a powerful tool to disseminate health information, engage with audiences, and make scientific material easier to comprehend and act on. In this way, opinion leaders such as bloggers may empower consumers with limited health literacy by making health information much more accessible, easier to evaluate, and therefore, more useful. Similarly, well-monitored online support groups, such as The Angiosarcaoma Project, can become trusted sources of health information.

However, the first two case studies suggest how health information sharing on social media platforms (online patient support communities, Instagram) also can complicate health decision-making and lead community members/followers to act on erroneous health information or flawed recommendations. Together, these case studies highlight the need for additional research about the benefits and drawbacks of sharing personal health experiences and information on peer-to-peer platforms.

Additionally, the first two case studies emphasize potential issues with echo chambers – either because dissenting voices are drowned out (as described in the patient support network case study), or because social media algorithms may prevent individuals from being exposed to dissimilar views (as described in the Instagram case study). When this occurs, it may prevent individuals from questioning false or non-evidence-based information, which reinforces their confidence to act based on misinformation.

The concerted efforts of health care providers, public health practitioners, and peer-to-peer network administrators are needed to identify effective strategies aimed at improving health literacy in a social media environment. Because the regulation of platforms in regard to misinformation is limited in the U.S. by First Amendment issues, a more reasonable and efficacious approach may be to engender consumers' personal agency by improving their health literacy levels. Using the example of Instagram 'clean eating' accounts, improved health literacy could help consumers distinguish between scientifically-informed nutrition advice and dubious claims. Given the need for more research and practical approaches to help improve the health literacy of the public, the authors next turn to individual and systems level interventions that help consumers navigate and evaluate online health information encountered on peer-to-peer platforms similar to those presented in the three case studies.

4. Interventions to support health literacy in online peer-to-peer contexts

Consider the hypothetical example of Janice, a woman with low health literacy, who has recently been diagnosed with lymphoma, a type of blood cancer. Wanting to learn more about lymphoma but not knowing where to start, Janice frantically searches online forums for information about the cancer, shares the diagnosis on her Facebook page where she seeks help finding a doctor, and uses Twitter to search for discussions about 'cancer cures'.

Janice quickly is confused by the conflicting information found through her searches and replies to her pleas. One Facebook page called 'Society of Natural Cures' claims her lymphoma can be cured by adhering to an alkaline diet, while an acquaintance hypothetically comments on her Facebook page she should try magnetic therapy. Janice's confusion is compounded by watching a YouTube video that teaches her about 'cupping', which is touted as an alternative cancer treatment in the video. At her appointment with an oncologist, Janice mentions the peer-provided information she found online only to be scolded by the provider for not trusting his advice and treatment recommendation.

What might happen if Janice had a higher level of health literacy from the outset of this difficult but commonly experienced situation? What factors might establish and foster the development of her health literacy in this context? For example, throughout her elementary education, Janice could receive instruction about how to recognize misinformation (e.g., distinguishing between legitimate and non-legitimate organizations) [29]. With this foundation, as Janice searches for information, she can more easily distinguish between credible and non-credible information found on these platforms.

Janice's health literacy could be addressed throughout her cancer information seeking experience by receiving notifications from Facebook when information she has viewed is flagged as potentially false and she is subsequently shown related articles that provide a different viewpoint on the same topic. Finally,

after discussing her information seeking experience with an oncologist, the physician could validate her efforts and provide an 'information prescription', which includes a list of online caregiver support networks, Facebook groups, and other websites where credible information about lymphoma can be found. The prescription preemptively addresses Janet's need for various types of social support (e.g., emotional support, instrumental support) in addition to meeting her information needs [30].

These contrasting scenarios highlight the need for different health-literacy interventions to help individuals navigate health information found on peer-to-peer platforms. Here, the authors take a health systems perspective on health literacy, noting that supporting health literacy efforts through effective interventions can and should occur both at the individual and information environment level [31,32]. The latter approach has been used most commonly in clinical healthcare settings [33]. Herein, the authors extend the context of the model to focus on the role of both individual-level 'activation' and system-level accessibility in the context of health information found in peer-to-peer platforms.

Below, the authors describe existing interventions and provide suggestions for additional interventions to support health literacy in peer-to-peer communication contexts. Educational initiatives and individual-level interventions are discussed first. Then, we turn to system-level interventions, focusing on clinical and industry initiatives.

4.1. Individual-level educational initiatives

First, there are efforts to promote health literacy within school curriculum reform initiatives. Most notably, the National Health Education Standards (NHES) was created to guide curricula development from kindergarten to 12th grade and encourages incorporating health literacy competencies into all public school disciplines [34,35]. Some school systems may also require health literacy as a competency for graduation [36].

Taking a developmental approach, the NHES sets benchmarks as children go through the public school system. For example, the approach says that by the age of 10, a child should be able to "describe how the media can influence health behaviors", and by 14, they should have the ability to "evaluate the validity of health information, products and services [36]".

To date, many of the examples of published K-12 curricula on health literacy have focused on helping students navigate the health care system with modules on understanding your medical history, finding a healthcare provider, and filling out medical forms [34]. While these topics are essential to a healthy and literate population, the authors contend that health literacy training also should include instruction to navigate an increasingly complex online information ecosystem [35].

Despite their nickname as 'digital natives', a need for K-12 online health literacy training was emphasized by a recent study by the Stanford History Education Group. The Stanford group conducted a series of experiments with middle-school and high-school students to study how students evaluated health and political information found in peer-to-peer platforms (e.g., Facebook, imgur). The researchers found most middle-school students were unable to distinguish between 'sponsored content' and an authentic news story. Similarly, more than 80% of high-school students did not critically evaluate a bogus image of 'nuclear flowers' on imgur, and more than 30% thought a fake news source was more credible than an authentic news source on Facebook [37].

Given the need to expand health literacy training, the authors propose health literacy curricula include examples and lectures that are specific to social media and peer-to-peer platforms. This training could include modules for topics such as: how to evaluate the source of health information found online (e.g.,

what a blue checkmark means on Facebook); how to critically evaluate health claims found on peer-to-peer platforms, and how to confirm health information by checking multiple sources.

4.2. Systems-level interventions

The authors contend it also is the responsibility of industry, clinicians, and health care systems to support patients/individuals to make evidence-based decisions and avoid adding more confusion. Here, the need is to change the design and tools available to individuals on peer-to-peer platforms in order to make health information more accessible and understandable, and to help consumers distinguish between credible and non-credible information.

4.2.1. Clinical initiatives

Clinic-based initiatives offer another opportunity to improve the health literacy of individuals and help them navigate peer-to-peer platforms. In order to optimize patient-centered communication, physicians and health care systems can utilize internet information to improve physician–patient interactions and relationships. As it becomes more common for patients and caregivers to find misinformation or claims on peer-to-peer networks, conversations with providers about the latter also are becoming more common. To prevent patients from coming across or accepting this misinformation in the first place, it may be helpful for physicians to refer their patients pre-emptively to trusted sources to ensure the quality of health-related internet information consumed by patients. These referrals are often called 'information prescriptions [38]'.

4.2.2. Industry initiatives

In April 2018, Mark Zuckerberg, CEO and Founder of Facebook, testified in front of the Senate. In his prepared opening remarks, Zuckerberg apologized for "not doing enough to prevent [Facebook] from being used for …fake news. It's not enough to just give people a voice, we have to make sure people aren't using it to hurt people or spread misinformation [39]".

Following his testimony, Facebook and other peer-to-peer platforms have tested and produced new industry initiatives to help users engage and interface with information found on social media. One initiative alerts users via a 'warning label' before they share a post, if other users have tagged the content as false or misleading.

Previously, Facebook released a 'related stories' algorithm which automatically displays additional news stories on the same topic below the original post [40]. A study by Bode and Vraga suggests correcting a post that contains misinformation using a related stories function, can reduce misperceptions about GMOs and illness, as well autism and vaccination [41]. Focusing on this strategy, the product manager for Facebook's News Feed tasked with reducing misinformation noted, "Even if something is false, we don't prevent people from sharing it. We give them context [42]".

In addition to these efforts, social media platforms are testing other initiatives to help individuals with lower health literacy navigate their services. For example, YouTube is rolling out a feature in India that shows individuals 'information panels' – text that provides verified information – along with videos when individuals search for information about topics that are prone to misinformation [43]. In addition to efforts that directly target misinformation, industry platforms also could provide tips regarding how to evaluate information or provide pro-bono campaigns so national health agencies and organizations can highlight legitimate news and reach a wide audience with health updates.

5. Conclusion

The democratization of communication has moved so quickly that researchers still do not fully understand its implications for health and health information seeking. In this chapter, the authors discussed and provided specific examples of the promise and potential pitfalls of increased peer-to-peer information, as well as introduced some individual- and system-level interventions to address health literacy. Advancing health literacy research is foundational to fully maximize the benefits and minimize the harm of the increased information access enabled by peer-to-peer platforms.

The need for the interventions discussed here will increase as the misinformation found on social media becomes more sophisticated – such as use of fake videos [42]. As health information and social media progress, individual and social health literacy efforts can help inoculate the public against health misinformation, and increase the effectiveness of public health campaigns and patient-provider communication.

References

[1] D.A. Broniatowski, A.M. Jamison, S. Qi, L. Alkulaib, T. Chen, A. Benton, S.C. Quinn and M. Dredze, Weaponized health communication: Twitter bots and Russian trolls amplify the vaccine debate, *Am J Public Health* **108**(10) (2018), 1378–1384. doi:10.2105/AJPH.2018.304567.

[2] S. Loeb, S. Sengupta, M. Butaney, J.N. Macaluso Jr, S.W. Czarniecki, R. Robbins, R.S. Braithwaite, L. Gao, N. Byrne, D. Walter and A. Langford, Dissemination of misinformative and biased information about prostate cancer on YouTube, *Eur Urol* **75**(4) (2018), 564–567. doi:10.1016/j.eururo.2018.10.056.

[3] J.P. Guidry, K. Carlyle, M. Messner and Y. Jin, On pins and needles: How vaccines are portrayed on Pinterest, *Vaccine* **33**(39) (2015), 5051–5056. doi:10.1016/j.vaccine.2015.08.064.

[4] M. Sharma, K. Yadav, N. Yadav and K.C. Ferdinand, Zika virus pandemic-analysis of Facebook as a social media health information platform, *Am J Infect Control* **45**(3) (2017), 301–302. doi:10.1016/j.ajic.2016.08.022.

[5] A. Smith and M. Anderson, Social media use in 2018. https://www.pewinternet.org/2018/03/01/social-media-use-in-2018/. Retrieved November 13, 2018.

[6] C.L. Bylund, J.A. Gueguen, C.M. Sabee, R.S. Imes, Y. Li and A.A. Sanford, Provider-patient dialogue about Internet health information: An exploration of strategies to improve the provider-patient relationship, *Patient Educ Couns* **66**(3) (2007), 346–352.

[7] A.L. Falisi, K.P. Wiseman, A. Gaysynsky, J.K. Scheideler, D.A. Ramin and W.S. Chou, Social media for breast cancer survivors: A literature review, *J Cancer Surviv* **11**(6) (2017), 808–821. doi:10.1007/s11764-017-0620-5.

[8] M.E. Waring, D.E. Jake-Schoffman, M.M. Holovatska, C. Mejia, J.C. Williams and S.L. Pagoto, Social media and obesity in adults: A review of recent research and future directions, *Curr Diab Rep* **18**(6) (2018), 34. doi:10.1007/s11892-018-1001-9.

[9] S.A. Moorhead, D.E. Hazlett, L. Harrison, J.K. Carroll, A. Irwin and C. Hoving, A new dimension of health care: Systematic review of the uses, benefits, and limitations of social media for health communication, *J Med Internet Res* **15**(4) (2013), e85. doi:10.2196/jmir.1933.

[10] W.Y. Chou, Y.M. Hunt, E.B. Beckjord, R.P. Moser and B.W. Hesse, Social media use in the United States: Implications for health communication, *J Med Internet Res* **11**(4) (2009), e48. doi:10.2196/jmir.1249.

[11] C.H. Lipset, Engage with research participants about social media, *Nat Med* **20**(3) (2014), 231. doi:10.1038/nm0314-231.

[12] E.B. Peterson, W.S. Chou, D.E. Kelley and B. Hesse, Trust in national health information sources in the United States: Comparing predictors and levels of trust across three health domains. *Transl Behav Med*, In press, doi:10.1093/tbm/ibz066.

[13] D. Ruths, The misinformation machine, *Science* **363**(6425) (2019), 348. doi:10.1126/science.aaw1315.

[14] W.S. Chou, A. Oh and W.M.P. Klein, Addressing health-related misinformation on social media, *JAMA* (2018). doi:10.1001/jama.2018.16865.

[15] S. Vosoughi, D. Roy and S. Aral, The spread of true and false news online, *Science* **359**(6380) (2018), 1146–1151. doi:10.1126/science.aap9559.

[16] Institute of Medicine of the National Academies. *Health Literacy: A Prescription to End Confusion*. The National Academies Press, Washington, D.C., 2004.

[17] http://www.centreforliteracy.qc.ca/health_literacy/calgary_charter. Retrieved July 20, 2018.

[18] E.G. Benotsch, S. Kalichman and L.S. Weinhardt, HIV-AIDS patients' evaluation of health information on the internet: The digital divide and vulnerability to fraudulent claims, *J Consult Clin Psychol* **72**(6) (2004), 1004–1011.

[19] A.J. van Deursen and J.A. van Dijk, Internet skills performance tests: are people ready for eHealth?, *J Med Internet Res* **13**(2) (2011), e35. doi:10.2196/jmir.1581.

[20] C. Knapp, V. Madden, H. Wang, P. Sloyer and E. Shenkman, Internet use and eHealth literacy of low-income parents whose children have special health care needs, *J Med Internet Res* **13**(3) (2011), e75. doi:10.2196/jmir.1697.

[21] S.R. Paige, J.L. Krieger and M.L. Stellefson, The influence of eHealth literacy on perceived trust in online health communication channels and sources, *J Health Commun* **22**(1) (2017), 53–65. doi:10.1080/10810730.2016.1250846.

[22] https://ascproject.org/home. Retrieved January 18, 2019.

[23] P.G. Turner and C.E. Lefevre, Instagram use is linked to increased symptoms of orthorexia nervosa, *Eat Weight Disord* **22**(2) (2017), 277–284. doi:10.1007/s40519-017-0364-2.

[24] E.V. Syurina, Z.M. Bood, F.V.M. Ryman and S. Muftugil-Yalcin, Cultural phenomena believed to be associated with orthorexia nervosa - opinion study in Dutch health professionals, *Front Psychol* **9** (2018), 1419. doi:10.3389/fpsyg.2018.01419.

[25] B. Wilson, Why we fell for clean eating, in: *The Guardian* 2017, [cited 2018 Dec 4]. Available from: https://www.theguardian.com/lifeandstyle/2017/aug/11/why-we-fell-for-clean-eating.

[26] U.S. Department of Health and Human Services and U.S. Department of Agriculture.*2015–2020 Dietary Guidelines for Americans*, 8th ed. 2015, http://health.gov/dietaryguidelines/2015/guidelines/.

[27] A. Burke-Garcia, G.L. Kreps and K.B. Wright, Perceptions About disseminating health information among mommy bloggers: quantitative study, *JMIR Res Protoc* **7**(4) (2018), e116. doi:10.2196/resprot.7764.

[28] K.B. Wright, C.L. Fisher, C. Rising, A. Burke-Garcia, D. Afanaseva and X. Cai, Partnering with mommy bloggers to disseminate breast cancer risk information: Social media intervention, *J Med Internet Res* **21**(3) (2019), e12441. doi:10.2196/12441.

[29] J. Orlando, How to help kids navigate fake news and misinformation online. http://theconversation.com/how-to-help-kids-navigate-fake-news-and-misinformation-online-79342. Retrieved November 1, 2018.

[30] J.P. Shipman, S. Kurtz-Rossi and C.J. Funk, The health information literacy research project, *J Med Libr Assoc* **97**(4) (2009), 293–301. doi:10.3163/1536-5050.97.4.014.

[31] D. Stokols, J.G. Grzywacz, S. McMahan and K. Phillips, Increasing the health promotive capacity of human environments, *Am J Health Promot* **18**(1) (2003), 4–13.

[32] B.W. Hesse and B. Shneiderman, eHealth research from the user's perspective, *Am J Prev Med* **32**(Suppl 5) (2007), S97–S103.

[33] K. Coleman, B.T. Austin, C. Brach and E.H. Wagner, Evidence on the Chronic Care Model in the new millennium, *Health Aff* **28**(1) (2009), 75–85. doi:10.1377/hlthaff.28.1.75.

[34] D. Hughes and K. Maiden, Navigating the health care system: An adolescent health literacy unit for high schools, *J Sch Health* **88**(5) (2018), 341–349. doi:10.1111/josh.12616.

[35] A. Matambanadzo, M. Manyard and T. Matambanadzo, Implementing a replicable model for K-12 health literacy to promote positive youth development, *J Consum Health Internet* **22**(1) (2018), 8–24.

[36] L.M. Sanders, J.S. Shaw, G. Guez, C. Baur and R. Rudd, Health literacy and child health promotion: Implications for research, clinical care, and public policy, *Pediatrics* **124**(Suppl 3) (2009), S306–S14. doi:10.1542/peds.2009-1162G.

[37] S. Wineburg, S. McGrew, J. Breakstone and T. Ortega, Evaluating information: The cornerstone of civic online reasoning. Stanford Digital Respository. http://purl.stanford.edu/fv751yt5934. Retrieved October 12, 2018.

[38] D.W. Kemper and M. Mettler, *Information Therapy: Prescribed Information as a Reimbursable Medical Service*. Healthwise, Inc., Boise, ID, 2002.

[39] M. Zuckerberg, Hearing before the United States Senate Committee on the Judiciary and the United States Senate Committee on Commerce, Science and Transportation. https://www.judiciary.senate.gov/imo/media/doc/04-10-18%20Zuckerberg%20Testimony.pdf. Retrieved February 5, 2019.

[40] M. Kranish, Facebook draws fire on "related articles" push. The Boston Globe. https://www.bostonglobe.com/news/nation/2014/05/03/facebook-push-related-articles-users-without-checking-credibility-draws-fire/rPae4M2LlzpVHIJAmfDYNL/story.html. Retrieved February 5, 2019.

[41] L. Bode and E.K. Vraga, In related news, that was wrong: The correction of misinformation through related stories functionality in social media, *J Commun* **65**(4) (2015), 619–638.

[42] G.A. Fowler, I fell for Facebook fake news. Here's why millions of you did, too. *The Washington Post*. https://www.washingtonpost.com/technology/2018/10/18/i-fell-facebook-fake-news-heres-why-millions-you-did-too/?utm_term=.850c4c9dd2b3. Retrieved February 10, 2019.

[43] P. Dixit, YouTube is rolling out a feature that shows fact-checks when people search for sensitive topics. https://www.buzzfeednews.com/article/pranavdixit/youtube-debunk-information-panels-india?bfsource=bbf_enus. Retrieved March 2, 2019.