

Social Media, Digital Health Literacy, and Digital Ethics in the Light of Health Equity

IMIA Participatory Health and Social Media Working Group

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Summary

Objective: Social media is used in the context of healthcare, for example in interventions for promoting health. Since social media are easily accessible they have potential to promote health equity. This paper studies relevant factors impacting on health equity considered in social media interventions.

Methods: We searched for literature to identify potential relevant factors impacting on health equity considered in social media interventions. We included studies that reported examples of health interventions using social media, focused on health equity, and analyzed health equity factors of social media. We identified information about health equity factors and targeted groups.

Results: We found 17 relevant articles. Factors impacting on health equity reported in the included papers were extracted and grouped into three categories: digital health literacy, digital ethics, and acceptability.

Conclusions: Literature shows that it is likely that digital technologies will increase health inequities associated with increased age, lower level of educational attainment, and lower socio-economic status. To address this challenge development of social media interventions should consider participatory design principles, visualization, and theories of social sciences.

Keywords

Social media, health equity, digital health literacy, ethics, accessibility

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1 Introduction

Since its emergence in 2004, social media is used by a growing percentage of individuals for health-related reasons [1]. Social media like Facebook, Instagram, Snapchat, Twitter, WhatsApp and YouTube became major sources for spreading health information and news in public. This health information might be relevant and correct, but also rumors are distributed which might lead to discrimination and misinformation [2, 3]. Interventions based on social media have demonstrated success in provoking behavior changes [4]. Social media data can be used in the context of digital phenotyping to profile the attitudes, behaviors, and health outcomes of people aiming at generating targeted communication interventions to influence health behaviors [5].

There are indications that social media interventions are effective to promote health equity since social media can remove geographic and physical access barriers [6]. Based on the World Health Organization's action guideline, health equity is defined as "the absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically or geographically" [7]. The current COVID-19 pandemic once more demonstrated that there are inequities

in healthcare: the pandemic is disproportionately affecting the poor, minorities, and a broad range of vulnerable populations [8]. Reasons for this include high prevalence of chronic conditions or poor access to high quality public health and medical care, which lead to a spread of the virus in areas of dense population and limited mitigation capacity [8].

Similar to healthcare, digital healthcare (including healthcare interventions based on social media) also has to be equitable [9]. Digital health inequities result from multiple factors, e.g., socioeconomic status and location, age, level of education, quality of social support network, and health literacy [10], cultural differences, or differences in social media access options. All these factors might affect the use and usefulness of social media interventions, which may result in health inequities. In this paper, we aim to assess the potential relevant factors impacting on health equity considered in social media interventions.

2 Literature Search

A literature review to identify potential relevant factors impacting on health equity considered in social media interventions was conducted on June 15th, 2021. A second search was performed on March, 23rd, 2022. A search strategy was defined combining keywords related to social media and health equity. Further details about the search engine are provided in Appendix 1 [see supplementary material]. Titles and abstracts of papers included in the PubMed database were automatically matched with the defined search string. Then, resulting papers were screened. First, titles and abstracts of those papers were reviewed by OR. In case of doubts, papers were passed to the next screening phase. Next, the full texts of included papers were obtained and reviewed by OR. In case of doubt, a second author, EG, independently reviewed them and a final decision was made by consensus. Studies were included if they reported some examples of health interventions using social media focused on health equity or if they analyzed health equity factors of

social media. Reviews and opinion papers that did not include examples of solutions or digital interventions using social media were excluded. A simple data extraction chart was defined and filled in with relevant information about health equity factors and targeted groups reported in the included papers. Factors identified were coded and grouped into categories.

3 Findings

3.1 Overview

We retrieved 158 unique results from the PubMed database search and 16 of those were found to be relevant for our analysis.

The factors impacting on health equity reported in the included papers were extracted and grouped into three categories: digital health literacy; digital ethics; and acceptability. Digital ethics was the most common category addressed in the included papers (N=10) [9, 11–19], followed by acceptability, which was included in seven studies [9, 10, 18, 20–23]. Digital health literacy was addressed in four of the included papers [9, 10, 19, 24].

3.2 Digital Health Literacy

For two decades, the World Health Organization has been concerned with health literacy as a health challenge across all parts of the world [25]. In the U.S., health literacy has been known to be an issue for a long time [26], with 90 million Americans estimated to have low health literacy. Americans with low literacy skills are four times more likely to report fair or poor health than persons with the highest literacy skills [27].

However, the need for health literacy, and in particular, critical health literacy – the ability to assess and question the information one receives – is crucial for policy makers, as well as for lay people. So is digital health literacy: to “synthesize, analyze, and appraise the vast amount of urgent, complex, and even conflicting information from virologists, epidemiologists, data modelers, doctors, nurses, health departments, and the media” [28].

Health literacy is not just an informational challenge, but one of public health. This occurs because of the functional aspect of health literacy. In fact, the name ‘health literacy’ may not fully convey the practical implications of this term, which extend beyond reading. According to the World Health Organization, health literacy implies the achievement of a level of knowledge, personal skills, and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions [29]. Thus, health literacy means more than being able to read pamphlets and make appointments. By improving people’s access to health information, and their capacity to use it effectively, health literacy is critical to empowerment.

Health literacy is itself dependent upon more general levels of literacy. Poor literacy can affect people’s health directly by limiting their personal, social, and cultural development, as well as hindering the development of health literacy.

Digital health literacy is much newer, and less studied. The paucity of literature is no indication of the topic’s level of importance, but of its novelty, as well as of the fact that many researchers study the use of digital health tools, without specifically mentioning health or digital literacy. In March 2020, telemedicine use increased 150% from the previous year as a result of practice changes related to COVID-19. The ability to avoid commuting was now coupled with avoiding physical contact, an important factor during a pandemic. Indeed, digital tools can increase safety, alongside access to care [30]. But the question arises: is this increased access equally divided, and are the digital tools contributing to lowering health gaps? The answer is not entirely optimistic. The people most likely to have health problems — including lower income, older, rural, and non-white Americans — also are most likely to struggle to use digital health tools [31]. They are less likely to approach such tools to begin with, including patient portals [32]. In light of this, the challenges in making digital health accessible start long before the design phase, and the way tools are presented to the public needs to account for hesitations and psychological barriers.

The use of digital tools for entertainment and communication is ubiquitous, but the transition from these domains to health tools that are easily intelligible, and applicable, is not trivial. The unique characteristics of digital health information, including context and complexity, make it challenging to communicate and understand.

In general, the literature indicates that it is likely that digital technologies will increase health inequities associated with increased age, lower level of educational attainment, and lower socio-economic status – but society is not there yet in regards to optimal use of digital health [33]. Sometimes, a hybrid approach is needed, such that mediates and facilitates the use of digital tools by various populations. For example, a study among German seniors, who have never before held a tablet or smartphone, encouraged them to use an adherence to an app that listed the medication they needed to take, and the times when they needed to check their blood pressure. The seniors had had a major health event and received several types of medication. The study team arrived in the seniors’ homes, gave each one a tablet, explained its use, programmed the specific senior’s medication regimen, and muted all other applications on the tablet. The seniors alternated between a month of using the app, and a month of using a traditional pen and paper medication journal. They preferred the digital version and have shown increased (self-reported) adherence to medication with it. This suggests that age-related digital health use gaps can indeed be narrowed [34], but that resources and planning are required for this to happen: The mere existence of digital tools does not guarantee their overall usage.

Some digital tools circumvent the need for health literacy in older populations and work directly with younger individuals, using seamless transfer of input from devices, with no need for the active involvement of the patient. For instance, Amazon recently launched a subscription service (Alexa Together) to help caregivers remotely monitor and assist seniors [35]. Amazon has been expanding its reach in the healthcare and digital health space in order to help multiple family members or caregivers to check on an aging loved one. They can set

customized alerts, such as a warning in case their family member hasn't used Alexa for a certain amount of time, and remotely help their loved one, like setting a reminder to take medications or managing a shopping list. Thus, this initiative is one example in how digital health is moving forward and expanding while considering various users' needs and limitations.

A 2015 inquiry of the 100 most popular health sites by the National Quality Health Website Survey evaluated the websites using evidence-based criteria for improving the user experience through design, organization, and content. Fewer than half of the websites (42%) met the pre-selected quality criteria [36]. This highlights the flipside of health literacy, digital and otherwise – the degree to which materials are clear and intelligible influences how well they are received and comprehended, in a way that places the responsibility on whoever provides such materials or designs such digital tools. This provides powerful support for the claims raised in a recent book [37]. Particularly in the chapter on health literacy ([37] pp. 73-98) the author claims that health literacy is a skill that both doctors and patients need, and that to increase participation, multiple stakeholders need to make a conscious effort. She offers takeaways for healthcare systems, so they can support patient comprehension. This involves, for example, tailoring materials for a fifth-grade reading level and creating institutional norms allowing patients to ask questions and use critical thinking. These conclusions also apply to digital health, where a conscious effort at creating accessibility for all health literacy and digital health literacy levels can improve health and reduce inequities.

3.3 Acceptability

Another identified factor impacting on health equity is related to technology. Digital health solutions could have unintended consequences for health equity. Both technological infrastructure and digital content might lead to issues that affect technology acceptance among some communities, especially in minoritized groups. This fact leads to reduced healthcare access, widen-

ing health disparities in those groups, exacerbating the digital divide and, therefore, reinforcing health inequity.

Although social media can potentially help to improve health equity, digital health solutions using social media must be carefully designed. Firstly, those solutions must be designed for all, facilitating access to healthcare to everyone independently of their characteristics and skills. In such circumstances, the adoption of Universal Design approaches led to more inclusive solutions, removing barriers in the access to digital healthcare among people with impairments. Therefore, accessibility, including cognitive accessibility, is key when designing those solutions.

On the other hand, racial and minoritized groups could perceive that solutions are not intended for them due to, for example, cultural differences. Rodriguez et al. reported that digital health tools have not been designed for marginalized populations [38]. In this situation, they could be reluctant to use those solutions, limiting their access to healthcare. So, issues such as cultural or gender are also relevant factors to be considered when designing social media-based health solutions. Cultural values and norms have been reported as relevant factors regarding acceptability in several studies [10, 39]. Ramirez et al. [20] analyzed data collected from a social media intervention aimed to promote advocacy for health equity among Latin people. The intervention was carefully designed following digital content curation, a process influenced by the Social Cognitive Theory, to create tailored online and social health information for an audience. The results demonstrated an effective dissemination of and exposure to culturally relevant information, suggesting that social media posts may be a powerful tool for public health campaigns for Latino health equity. Depres et al. [21] used the digital content curation model to create and communicate culturally relevant information to raise awareness and generation action against the COVID-19 pandemic's inequitable impacts on Latin people.

Following a User-Centered Design approach involving patients who represent all targeted communities may support the development of those solutions enabling the iden-

tification of potential problems from early stages. Crawford and Serhal recommended the involvement of people from marginalized groups in co-design as a relevant strategy to take into account their values and cultural norms and preferences for digital resources [9]. Population-specific preferences have been reported as a relevant factor in the acceptability of social media intervention [40]. User-Centered Design proposes an iterative process of design and evaluation that allows to gather data in real settings, which is defined as a key recommendation by Friis et al. [10]. Additionally, acceptability testing could be conducted in the evaluation stage increasing the likelihood of adoption by target population as it is recommended by Welch et al. [6]. Several examples of contextually tailored, sociotechnical mobile health interventions designed with community members to address health inequities were presented by Brewer et al. [22].

Data Visualization

For health equity to be achieved, there is a clear need to make health information understandable to people who have a broad range of educational backgrounds. Online tools such as Google Scholar provide information that, while of interest, may be very technical and difficult to interpret. Patients increasingly are involved in making decisions about their care, and the greater the uncertainty about which treatment is best, the more likely they will be asked to choose [41]. Methods of information presentation that are easy to understand increase the opportunity for people to choose treatments that satisfy them and improve their quality of life. One way that this goal can be achieved is through the use of data visualizations.

Graph literacy is the ability to understand information that is presented as sketches, photographs, diagrams, maps, plans, charts, graphs, and other non-text, two-dimensional formats [42]. The ability to understand graphs requires three skills: information extraction, information interpolation and interpretation, and information extrapolation and analysis [43]. Although health literacy specialists recognize the importance of graph literacy, much less is known about it than about text literacy or number literacy (numeracy). Some work

suggests that people with lower numeracy skills may be less able to interpret graphs [44], but other work comparing the likelihood of events in different numerical formats indicated that graphs may help portray risk to people who have low numeracy [45, 46]. However, not everyone finds graphs easier to interpret [47], and graphs may not always result in better understanding of health risks in those who accurately grasp risk before looking at a graph [48]. Reducing users' cognitive work by limiting the number of visual elements and highlighting the most important details helps people to interpret data no matter what literacy skills or socioeconomic background they possess [49].

Data visualizations can support acceptability by easing the interpretation tasks people must perform when given health information. For example, the use of infographics (i.e., pictographs) can increase understanding of health-related concerns [50]. Highlighting concepts that people already understand and reducing the knowledge distance between medical professionals and patients improve grasp of medical information [51] and thus can improve understanding. There is some evidence that pictographs are the most desirable format for presenting probabilistic information when patients and the care team make decisions together [52].

3.4 Digital Ethics

Equity in health is an ethical concept grounded in the principles of distributive justice [53]. Equity in health is defined as “the absence of systematic disparities in health between social groups who have different levels of underlying social advantage/disadvantage” [53].

Technologies such as social media can potentially help to improve health equity. Social media were not created for health purposes; however, many of their users are getting the advantage of using them with different aims, including health and health-related issues. Social media are ubiquitous, very easy to use, and most of them are freely available, which facilitates its access to a large part of the population, including members of minorities, underserved, and vulnerable communities.

However, access to social media and levels of digitalization worldwide are unequal. Heterogeneity in digitalization levels has a clear impact on health inequalities. The World Health Organization on their 2020-2025 global strategy propose a strategy plan on digital health to support equity in access to digital resources [54].

Literature shows that funding initiatives have been developed to accelerate the use of social media as strategy for increasing health equity [19]. Several frameworks and models involving the use of social media and digital health have also been created to address health equity for underserved communities [9, 13, 17].

Several benefits and challenges linked to the use of social media and digital health to improve health equity have been discussed in the literature. Some of the reported benefits of technologies for improving health equity include:

- Strengthening relationships between minority groups members and health providers [18];
- Formation of health literacy interest groups and networks [55];
- Increasing awareness and engagement with health contents [11, 20, 23] and also with health policy strategies [16];
- Promoting health and wellness [20, 21, 24];
- Providing continuity of care outside the clinic [24].

Trying to improve health equity through digital technologies is not exempt from risks. Among the challenges of using social media and digital health, these topics are discussed in literature:

- The possibility that health literacy interest groups could fade out without impact [55];
- A possible disconnection between health professionals and researchers wanting to achieve health equity but not being equipped with the know-how [16];
- A willingness to engage with digital technologies that can be affected by social determinants in some cases, which could exacerbate some healthcare inequities [56]. As a response to this challenge, two programs and strategies for implementation of smartphone loaner system have been proposed [13, 15];
- Possible security and privacy implications [15].

4 Conclusions

Digital health inequalities can result from multiple factors, such as socioeconomic status and location, age, level of education, quality of social support network, health literacy, cultural differences, or differences in social media access options. All these factors might affect the use and usefulness of social media interventions which may result in health inequities.

Literature shows that it is likely that digital technologies will increase health inequities associated with increased age, lower level of educational attainment, and lower socio-economic status.

Digital health solutions could also have unintended consequences for health equity that might lead to issues that affect technology acceptance, especially among minority groups or underserved populations, thereby reducing their access to healthcare, widening health disparities in those groups, and exacerbating the digital divide. Data visualizations can support acceptability by easing the interpretation of health-related content.

In addition to the challenges linked to the use of social media and digital health on health equity; some benefits have also been discussed in the literature. Social media can promote health equity by strengthening relationships between underserved populations or minority groups and healthcare providers, by increasing health literacy, or by providing continuity of care through these channels.

To address the challenges, developers and providers of social media-based health interventions should consider the following recommendations:

- Apply principles of social sciences, user-centred design and participatory design during development of social media interventions;
- Tailor content to the user group considering cultural aspects, age, and gender as well as cognitive restrictions;
- Use appropriate visualizations for content;
- Educate patients and health professionals in using digital interventions, particularly their benefits and challenges;
- Test acceptability.

As researchers and innovators working in digital health, we have a duty to help improve

health equity. We are encouraged to design for diverse populations [10]. We should also integrate and actively involve minorities, undeserved, and vulnerable communities [12, 22] to truly achieve health equity for all. And last but not least, we must continuously assess the use of social media and digital technologies for health and their usefulness in relation to their short- and long-term ethical, health equity, and social justice implications [14].

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