

## REVIEW ARTICLE

# The Role of Social Networking in Improving Health Literacy in Online Community: A Scoping Review

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## ABSTRACT

This review aimed to identify the role of social networking in online communities to improve health literacy. We searched used electronic databases, namely Pubmed, EBSCO, Cochrane, Proquest, and Embase, from January 2012 to January 2022. Identification and screening were independent according to selection criteria. The electronic searches turned to 1.811 articles, nine of which met the inclusion criteria and were selected for study analysis. The findings showed that the roles of social networking in online community programs are Accessible avenues for information and experience sharing, self-managed care, social, emotional, psychosocial, and technical support. This scoping review concludes that social networking in online community programs can improve health literacy.

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## INTRODUCTION

The rise of digital media makes it simple for everyone to participate in the information cycle as both a consumer and a content producer. It is anticipated that the gap in health information will be reduced or eliminated thanks to new media. However, the proliferation of health hoaxes on social media is just one example of how varied information offered, made possible by the convenience of the digital age, has resulted in new challenges. Researching this topic in the new media age requires a distinct reading strategy because it can develop. Hoaxes on medicine and health care are highly hazardous since they deal with life and human rights. (1). A sufficient level of health literacy is related to numerous positive health outcomes, including reducing the risk of morbidity and mortality and the likelihood of needing emergency care (2). Health literacy should be a central policy strategy to bridge health inequalities, especially in developing countries (3).

Although social media was one of the sources of hoax circulation (1), it also became a social network that

was increasingly needed and used as a reference for accessing news and information (4). In order to satisfy their requirements for health-related information, a rising number of people are becoming active members of online health communities. An online health community member participates in a virtual discussion group called a health community because they share a shared interest in many aspects of health (5). One fresh approach to achieving this objective is to use emerging technologies to facilitate improved two-way communication between patients and the medical professionals who treat them. Technology can potentially improve patients' access to care and the social capital required to participate actively in their care (6).

In the field of research, netnography is used for studying online discussions. The modern qualitative research approach known as netnography is used in various industries as an ideal method to evaluate and comprehend an online person. (7). The evolution of social media and its relationship to netnography are inextricably interwoven. (8).

The netnography procedures include five steps. First, use search engines to narrow in on the precise virtual communities and research questions that need to be answered (7). Second, accumulating information on

virtual communities and analyzing in-depth observations, interactions, and interpretations of virtual community members. Third, prioritize dependability over validity and concentrate on classification, coding, reporting, and triangulation procedures. Fourth, clarify the presence of members of the online community during any research, ensure the confidentiality and anonymity of informants, solicit and incorporate feedback from members of the online community being researched, and take a cautious stance on the private versus public medium issue. Fifth, presenting some or all of the findings of the final research report to the members being studied to solicit their feedback.

Netnography combines different methods in a single approach (8), essential in shaping the understanding of the internet and its impact on cultures and vice versa. One netnographic study showed that online communities are the source of valuable and reliable peer support and medical advice. Patients who receive psycho-affective support from online interactions can improve their understanding of disease and its management (9), which may support the improvement of health literacy. As customized interventions to increase the efficacy of antiretroviral therapies, online social networks can, for instance, promote health literacy and medication adherence in the HIV care continuum. (10). Numerous studies have been conducted to investigate the function of the social community in health-related issues, namely for reducing attrition from online health behavior change interventions in low social support populations (11); supporting social online community that effect on positive self-efficacy, self-esteem and subjective well-being (12); encouraging knowledge and support among a population that needs to optimize its disease self-care (13); and sharing informational resources, personal experiences, and emotional support, as well as a community with their peers (14).

A netnography article shows that social media can play an important role in correcting misinformation and be a valuable tool for medical learning and supporting patients (9). Netnography is crucial for analyzing interactions on social media, especially in improving health literacy in online communities. More studies in the field of netnography are needed. Based on the previous, this scoping review aimed to identify the function of social networking in online communities in improving health literacy from a netnography standpoint.

**METHOD**

**Strategy of literature search**

The Google Scholar, MEDLINE, CORE, and Scopus databases were searched for related studies published prior to 2021 for this literature review. The following keywords were used in the research: “Customized knee prosthesis” and “patient-specific knee prosthesis” are terms used interchangeably.

**Criteria for inclusion and exclusion**

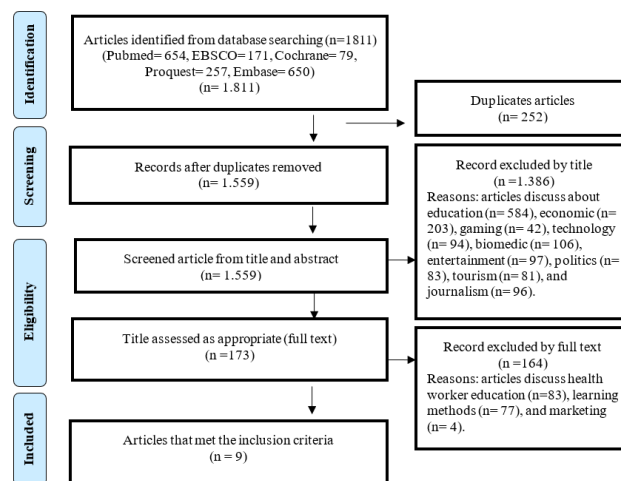
For the inclusion criteria – (1) Papers published in English only were included. (2) Paper is intended to include papers from 2009 to 2020 (3) Only Total Arthroplasty was considered for review (4) Studies should include biomechanical aspects (5) Studies should be original and duplicates of previous literature.

For the exclusion criteria the following were taken into consideration – (1) Studies containing Uni-compartmental or bi-compartmental Arthroplasty were not included (2) Studies comparing different geographies should not be included. (3) Arthroplasty on animals is not considered (4) Implants designed for animals are not included.

**RESULTS**

A total of 1,811 articles were judged to be relevant to the keywords after the search results were compiled from five different databases. Furthermore, 252 articles were removed due to duplication, and 1,559 articles were reviewed based on title and abstract. After screening the title and research abstract, 173 publications met the requirements and were discovered in the full text. Only nine papers could be continued for analysis based on the inclusion criteria. Discussions about education, economics, gaming, technology, biomedicine, entertainment, politics, tourism, journalism, health worker education, learning methodologies, and marketing are reasons for removing articles. Figure 1 depicts the PRISMA flow, which explains the search technique, article eligibility, and publications included in the study.

Data extraction was performed by analyzing data based on the author’s name, the journal’s name, the title, the purpose, the variables, the research method, data collection, research outcomes, and the conclusion. Table I displays the outcomes of data extraction.



**Figure 1: The article selection process**

**Table I: Summary of reviewed articles**

Author, year	Title	Purpose	Method	Results
Suanrueang, et al. (2022) (18)	The impact of the covid-19 pandemic on anxiety, health literacy, and eHealth literacy in 2020 related to healthcare behaviour in Thailand	To characterize causative factors of anxiety, health literacy, eHealth literacy, and protection in the new normal of COVID-19 pandemic in Thailand	Cross-sectional quantitative study using a non-systematic sampling method to investigate the three main variables (anxiety, health literacy, and eHealth literacy) influencing preventive health behaviour related to coronavirus disease.	Those who are more concerned and literate about health literacy and eHealth literacy, will make better health decisions and practice more preventive health care.
Jurich, E.K (2021) (19)	'Do you think this is normal?': risk, temporality, and the management of children's food allergies through online support groups	To investigate how mothers engage with issues of allergy-related risk in an online community, to carry out the daily process of managing risks and making decisions relating to the diets of babies with food allergies.	An Internet-based qualitative methodology (Netnography)	The different practices mothers employed to transform emergent allergic situations into manageable decisions with the help of other mothers online
Bira, et al. (2020) (22)	Social Support Mediated by Technology. A Netnographic Study of an Online Community for Mothers	To describe an online community of mothers, aiming at capturing the mechanisms of social support in the group, and also, schematically, the changing norms of motherhood they are related to.	Netnography	The physiognomy of support is related to changing normative models of motherhood. In helping each other, the mothers also expressed their difference from older generations, and their personal and professional aspirations.
Gavrila <i>et al.</i> (2019) (20)	Peer Support Through a Diabetes Social Media Community	To assess how the online community impacted peer support	Qualitative study using semi structured qualitative interviews.	Members of the CGM in the Cloud Facebook group identified peer support through giving and receiving technical, emotional, and medical support, as well as giving back to the larger community by paying it forward. Peer support also extended beyond the online forum, connecting people in person, whether they were local or across the country
Haik <i>et al.</i> (2019) (14)	The Online Support Group as a Community: A Thematic Content Analysis of an Online Support Group for Idiopathic Subglottic Stenosis	To better understand the content shared in a busy online community for individuals with iSGS.	Thematic content analysis using conventional qualitative analysis model.	Three major thematic elements resulted: (1) information sharing; (2) emotional support, expression, and experience sharing; and (3) community building. A significant portion of group members requested information from their peers, suggesting a high level of trust toward the resources provided in this group, even those involving a surgical procedure or medication.
Litchman et al. (2018) (13)	Effect of Diabetes Online Community Engagement on Health Indicators: Cross-Sectional Study	To survey adults with diabetes who participated in the diabetes online community to better understand and describe who is using the diabetes online community, how they are using it, and whether the use of the diabetes online community was associated with health indicators.	Cross-sectional study using online survey by posted a synopsis of the study with a link to the survey on the principal investigator's TuDiabetes profile page, which was shared by key opinion leaders and mentioned in the TuDiabetes online newsletter.	Diabetes online community engagement was a strong predictor of A1c, reducing the odds of having an A1c $\geq 7\%$ by 33.8% for every point increase in diabetes online community engagement (0-5). Participants are oftentimes (67.2%, 123/183) not informing their healthcare providers about their diabetes online community use even though most (91.2%, 161/181) are seeing their healthcare provider on a regular basis.
Diniz <i>et al.</i> (2018) (9)	Experience With the Use of an Online Community on Facebook for Brazilian Patients With Gestational Trophoblastic Disease: Netnography Study	To describe the netnography of Brazilian patients with GTD on Facebook (FBGTD) and to evaluate whether their experiences differed depending on whether they received care in a Brazilian gestational trophoblastic disease reference center (BRC) or elsewhere.	A cross-sectional study using G Suite Google Platform and a netnographic analysis.	Reference center patients (RCP) felt safer and more confident at the time of diagnosis of GTD ( $p=.001$ ). RCP were more likely to utilize FBGTD after a referral by health assistants ( $p<.001$ ), whereas NRCP more commonly discovered FBGTD through Web searches ( $p<.001$ ). NRCP had higher educational levels ( $p=.009$ ) and were more commonly on FBGTD for $\geq 6$ months ( $p=.03$ ).
Flickinger <i>et al.</i> (2017) (21)	Social Support in a Virtual Community: Analysis of a Clinic Affiliated Online Support Group for Persons Living with HIV/AIDS.	To investigate how social support was exchanged in a group of 55 participants over 8 months, using an adaptation of the Social Support Behaviour Code.	Qualitative study using Interviews.	Messages providing support were predominantly emotional (41 %), followed by network (27 %), esteem (24 %), informational (18 %), and instrumental (2 %) support.
Lobchuk <i>et al.</i> (2015) (17)	A Qualitative Analysis of "Naturalistic" Conversations in a Peer-Led Online Support Community for Lung Cancer	To describe the content of messages in a United States-based online support community for lung cancer.	Descriptive exploratory qualitative approach using descriptive analysis of posting content.	Most users were female and equally divided as patients or support persons. Content analysis generated nine themes: disease information, diagnostic test information, treatment information, symptoms, marked deterioration, advocacy, experiencing healthcare providers and the system, positive survivorship, and making sense of emotions.

According to the findings of the scoping review, the responsibilities of social networking in online community initiatives are as follows: as accessible outlets for knowledge exchange and non-judgmental emotional support (17); scaling up health literacy during pandemic situation (18); improves social support for decision making from peers (19); as a supplement to usual healthcare activities that may encourage knowledge and supports and a strong predictor of health indicators (13); as supplement care for the patient (9); as routes for peer support through emotional and technical assistance, and as an empowering tool (20); increase the reach of groups that are unable to receive in-person support and may improve care (21); as a powerful resource for information sharing, emotional support, experience sharing, and community building (14); and as a social support system for the member (22).

## DISCUSSION

Based on the research results, the authors summarize the roles of social networking in online community programs into three findings, including accessible avenues for information and experience sharing; self-managed care; and social, emotional, psychosocial, and technical support.

### Accessible avenues for information and experience sharing

Since the advent of the internet, there has been a rise in virtual and online communities (23). Due to the increasing number of virtual communities, it has become easier to exchange information with many people. Many people participate in virtual communities to acquire a piece of information or solve their problems. Virtual communities have provided a forum for patient communication. Furthermore, this virtual technology facilitates reaching populations with direct support barriers and is a valuable, accessible information exchange platform (21).

Sharing information and experiences centered on patients is one of the most prominent aspects of the internet environment of the present day. This trend has developed with the proliferation of blogs, online communities, and social media platforms. Patients who wish to engage in sociability and the sharing of knowledge can do so through the use of what are known as online support groups or virtual communities (7). According to Eysenbach et al (24) patients with similar interests or ailments meet digitally to share their health experiences, ask questions, or provide emotional support and self-care.

A typical health virtual community is a group of people (patients, doctors, professionals, and members of the general public) who have gathered to share health-related information and personal experiences (25). Nowadays, the most well-known platform is patient-

led sites that provide support and information. They usually include a moderated forum, blogs, guidance, assistance, academic references, and a store where may buy relevant things. IBD Relief (a platform focused on inflammatory bowel disease), Care Opinion (which allows patients, caregivers, and health care staff to share stories of care and develop solutions for problems across the system), Patients Like Me (which pools patient feedback about the efficacy of therapies, side effects, and disease progression for the benefit of patients and clinicians, industry players, and academics), and Genetic Alignment are some examples of patient-led platforms (26).

### Self-managed care

Online communities can be an acceptable approach to prevent non-adherence in online health interventions related to health behavior change, especially in areas with low social support (11). A study of patients with gestational trophoblastic illness found that a web-based doctor-patient connection helped supplement patient care, particularly for patients treated in underserved healthcare institutions (9). Health-related information sharing has become necessary for people with severe illnesses in Turkey, where support groups based on interaction with others with similar issues are widespread among those with serious illnesses (7).

Virtual communities for certain conditions have grown in popularity and importance in recent decades, as social media platforms have enabled sufferers to educate and support themselves (7). It has enabled individuals with chronic or life-threatening diseases to self-manage their health at home or remotely from the point of care, giving rise to the concept of self-managed care. Therefore, the capacity to provide care and support to patients (or potential patients) at a distance from medical facilities is crucial (27).

In a pandemic, individuals can use their health knowledge to make protective decisions. Additionally, they can use what they have learned on social media to protect themselves from other emergent infectious diseases. It is necessary to make practical, timely, readily accessible, and prioritized health information available in electronic format on multiple social media platforms to educate people on preventing the spread of disease (14). According to Gadelkarim et al., after emerging from the pandemic, social media is here to stay, and residency healthcare programs will continue to adapt to the changing digital world. On the other hand, it can maximize the virtual reach and develop social media health education (28). Social media offers the opportunity for either government or public health officers to analyze public attention to risk communication and epidemic control measures after the pandemic (29). Digital health after the pandemic is crucial to improve existing solutions while improving infrastructure and building new solutions to reach even

the unreachable population in Indonesia and to recover together and recover stronger (30).

Social, emotional, psychosocial, and technical support Virtual communities serve many purposes, including information gathering, social interaction, experience sharing, concern sharing, and psychological support (31). An online community is a forum for sharing information, personal experiences, and emotional support from others (14). Online communities could provide emotional and technical peer support and serve as an instrument of empowerment (20). Connection and support are perceived as the most important benefits of online communities (21). For example, people who are highly involved with diabetes online communities tend to have lower glycaemic levels than those who are less. Participation in diabetes online communities is associated with improved health-related quality of life and more excellent diabetes-related self-care (13).

Online communities are feasible and safe as potential psychosocial interventions for post-transplant adolescents. Qualitative data indicate an increased sense of normalcy, self-confidence, contribution to society, and increased social networking in the patient (27). In addition, patients who participated in both online communities and face-to-face support groups were the ones who received the highest levels of social support from their contemporaries. Factor analysis showed that the group using two sources of support had a higher score in emotional support scores, insights, advice, and assistance (33).

An online health community, exemplified by interactive communication, is essential for patients to acquire disease-specific information and share their experiences. Chen, Chang & Liu (34) state that "Typically, virtual communities emerge as a result of participants gathering online to discuss topics such as a shared hobby, a medical condition, a personal emotion or experience, or even the formation of new relationships. A virtual community facilitates member interaction and communication." Regarding the relationship between online community roles with health literacy, according to a study conducted by Zhou and Wang (30), pursuing health knowledge, contributing to health knowledge, and receiving emotional support were all positively correlated with e-health literacy. E-health literacy is positively associated with the interaction effect between health knowledge and emotional support.

The authors of this scoping review acknowledge the following limitations. The evaluation was restricted to publications written in English. It may have excluded the function of social networking in non-English journal articles about online communities. The strength of this research lies in pioneering the use of netnography, particularly significant as the digital world is rapidly evolving. Furthermore, future studies could expand this

by conducting a systematic literature review on health literacy, particularly focusing on quasi-experimental designed research.

## CONCLUSION

Considering the essential roles of social networking in online community programs from a netnography's view, including accessible avenues for information and experience sharing; self-managed care; and social, emotional, psychosocial, and technical support, authors conclude that social networking in online community programs may improve health literacy.

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