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Influence of Health Social Networks on Healthcare: A Systematic Literature Review

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Abstract

Chronic diseases account for 71% of mortality across the globe. Health systems in both developed and developing countries are constrained in their ability to deal with the increasing incidence of chronic diseases due to the global shortage of healthcare professionals. Consequently, health social network sites (HSNs) are increasingly being used by patients and caregivers to search for health information and provide social support to one another. This paper presents the results of a systematic literature review (SLR) aimed at exploring the benefits and drawbacks of HSNs. Thirty-four research papers retrieved from five electronic databases were analyzed using specific inclusion/exclusion and quality assessment criteria. The results showed that all the 34 papers included in the SLR were published by authors from developed countries. Using thematic analysis, the benefits identified were classified broadly as (i) provision of health information and (ii) social support. The drawbacks include the dissemination of health misinformation, feeling of marginalization by healthcare professionals and concerns over privacy and confidentiality of health information. The research results highlight a need for studies that focus on the use of HSNs by researchers from developing countries and create a unique opportunity for African researchers to leverage the continuing growth in the number of active social media users to address the shortage of healthcare professionals in the continent.

Keywords

Health social networks, health social support, HSNs and healthcare, online health communities, social media for health, systematic literature review.

1 Introduction

According to the World Health Organization (WHO), 71% of global deaths are caused by chronic diseases like cardiovascular conditions, diabetes and cancers (WHO, 2021). Several studies have reported on the shortage of healthcare professionals in developed and developing countries (Miseda et al., 2017; Wu et al., 2016). A consequence of this shortage is an increase in the demand and use of the internet to search for health information (Amante et al., 2015; Zhao et al., 2021; Zhao & Zhang, 2017). In their research, Grosberg et al. (2016) found that 70% of internet searches were related to health information. According to Kemp (2021), as of January 2021, there were 4.66 billion internet users globally, with 4.2 billion being active social media users. In the same period, South Africa had 38.19 million internet users with 25 million being active on social media platforms. The increasing use of the internet and the abundance of health-related information online have led to the rise of health social network sites (HSNs). HSNs or online health communities (OHC) are websites where people connect to find health resources and services, ranging from emotional support, question and answer (Q&A) with physicians or information on clinical trials that they could partake in (Kotsilieris et al., 2017; Swan, 2009). Social media has the potential to empower individuals to modify or change their unhealthy behaviours and promote positive health outcomes (Hunter et al., 2019; Korda & Itani, 2013). Furthermore, HSNs can break down geographical barriers through access to health information and social support without regard for time or privacy constraints (Johnston et al., 2013; Yan et al., 2016).

Participants of HSNs can include individuals with specific diseases, family members, groups of healthcare professionals with common interests, and non-professional caregivers (Mehta & Atreja, 2015). Some of these HSNs are dedicated to individuals with specific chronic illnesses (e.g. TuDiabetes and WarOnCancer). Others have a broader focus and cater for anyone with any chronic illness (e.g. PatientsLikeMe and CureTogether). Still, others are specifically designed for those who wish to modify a specific health-risk behaviour (e.g. quitting smoking) or other health-related lifestyle variables like losing weight (Laranjo et al., 2015). HSNs also enable access to online consultations, facilitate social connections and the generation of big data for the advancement of medicine. For example, patients can create profiles on HSN sites like PatientsLikeMe to capture and monitor their progress. Users can also share their health information with other people or their healthcare professionals. HSNs allow users to connect with people with the same health condition, whilst also providing access to information on clinical trials and other health-related information (Santoro et al., 2015).

Individuals with health conditions typically build connections more easily with each other when they are at a similar stage of illness or recovery, as they can provide each other with relevant support (Centola, 2013). The rise of HSNs enables people to form groups and capitalize on the power of ‘community’. These sites have become essential in raising awareness on various health conditions and their management, with some websites and groups raising funds for organisations or individuals (Ventola, 2014). HSNs act as a driver of behavioral change through self-regulation, patient activation and participatory health (Gao et al., 2019; Syed-Abdul et al., 2016). Self-regulation entails the incorporation of behavioral changes into one’s everyday life (Syed-Abdul et al., 2016). Patient activation on the other hand relates to the extent to which an individual has the requisite knowledge, skills and confidence to self-manage their health or disease (Gao et al., 2019), while participatory health deals with active collaboration between healthcare professionals and a patient in the decision-making process on the appropriate treatment strategies (Syed-Abdul et al., 2016).

Given the increase in the use of HSNs, the purpose of this paper is to report on a systematic literature review (SLR) aimed at exploring the benefits and drawbacks of their use. The remaining sections of the paper are organized as follows: Section 2 provides a detailed narration of the SLR process, including the research question, inclusion/exclusion criteria, source selection and quality assessment of the research papers included in the SLR. The results from the analysis of the 34 research papers included in the SLR is in section 3. Section 4 concludes the paper by highlighting the study’s contribution, limitations, implications for healthcare professionals in terms of their role in the use of HSNs, and recommendations for future research.

2 Systematic Literature Review Process

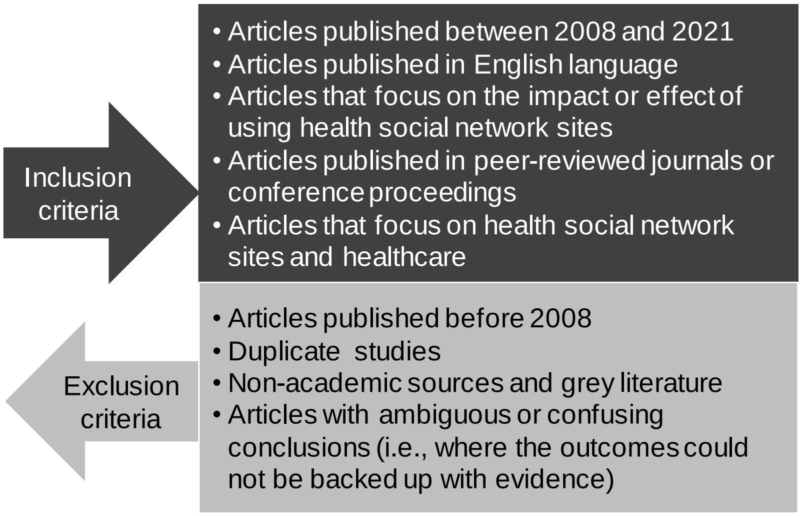
The SLR followed the updated Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guideline (Page et al., 2021) and the SLR guide by Siddaway et al. (2019). The main research question that is addressed in the paper is: "*What are the benefits and drawbacks of health social networks on healthcare"?* The SLR process was scoped by retrieving peer-reviewed research papers from the following electronic databases:

- IEEE;
- National Centre for Biotechnology Information (NCBI);
- PubMed;
- ScienceDirect; and
- SpringerLink.

These databases were selected because of their reputation in publishing quality and high impact journal and conference papers on biomedical research. To ensure the retrieval of relevant papers, the following combination of search phrases were used: ("health social networks") OR ("social health networks") OR ("*health*soci*netw*") OR ("online health communit*") AND ("influence" OR "behaviour" OR "effect").

2.1 Inclusion and Exclusion Criteria

To make the search process more manageable, the research papers were filtered using the inclusion and exclusion criteria in Figure 1.



- Articles published between 2008 and 2021
- Articles published in English language
- Articles that focus on the impact or effect of using health social network sites
- Articles published in peer-reviewed journals or conference proceedings
- Articles that focus on health social network sites and healthcare

- Articles published before 2008
- Duplicate studies
- Non-academic sources and grey literature
- Articles with ambiguous or confusing conclusions (i.e., where the outcomes could not be backed up with evidence)

Figure 1: Inclusion and exclusion criteria

2.2 Source Selection and Quality Assessment

The search period for the SLR was between March and September 2021. To ensure that the number of potential sources that could be screened for eligibility is more realistic, the source selection process was restricted to the electronic databases listed in section 2. A total of 1157 records were found by searching the databases. Twenty-one additional sources were found through sources cited in the research papers that were retrieved, yielding a total of 1178 records. Twelve duplicate records were removed, leaving 1166 records as eligible for further screening. The remaining 1166 records were then screened by title, abstracts and keywords. This process resulted in 1030 records being eliminated. A total of 136 full-text articles were further screened for eligibility, after which 95 additional records were eliminated.

The remaining 41 articles were assessed using the following quality assessment (QA) criteria:

- Is the methodology of the article clearly defined?
- Does the article explain or define health social networks and healthcare?
- Does the article discuss or explain the possible and negative aspects of using health social networks?
- Does the article assist in answering the research question of the current study?

Each article was assigned the value “yes = 1” if it fully met a QA criterion, “partially = 0.5” if it met a criterion partially, and “no = 0” if it did not meet a criterion at all. Thus, each article could have a maximum score of 4 if it fully met all the QA criteria. Subsequently, articles that obtained between 3.5 and 4 points were classified as “high”, those with scores between 2 but less than 3.5 were classified as “medium”, while the ones with scores below 2 were classified as “low”. Only articles that were classified as high and medium were included in the SLR. The QA process resulted in seven additional sources being eliminated, with the final set of 34 being included in the SLR. Figure 2. illustrates the source selection process.

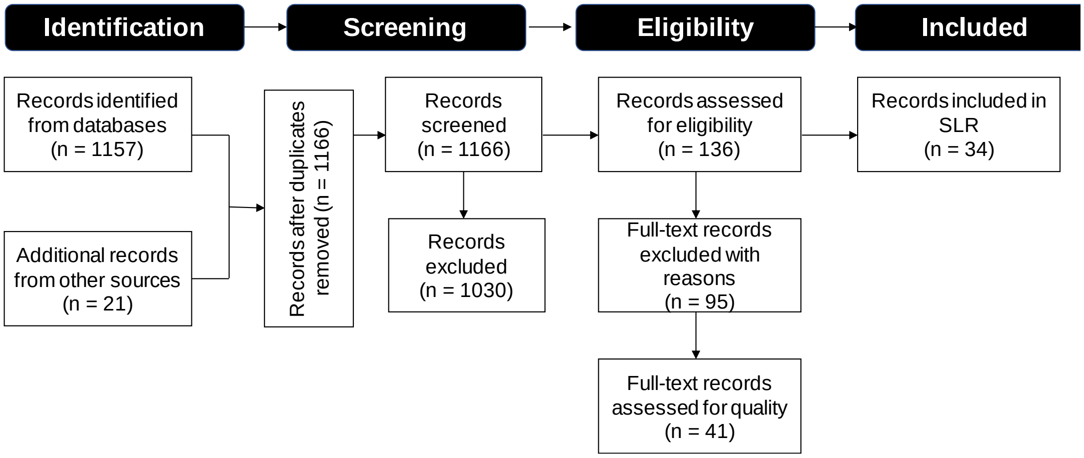


Figure 2: Source selection process

3 Results and Discussion

This section gives a detailed discussion of the results obtained from the analysis of the 34 research papers that were included in the SLR.

Quantitative analysis of the 34 research papers using descriptive statistics showed that there was an increase in the publication of research papers that focused on the use of HSNs in 2013 and 2014 with four publications in each year. There was a slight dip in 2015, with three publications. The highest publications (five) were in 2016 and 2017 (see Figure 3). Thereafter, the numbers tapered down substantially with one paper each in 2018 and 2019, before picking up in 2020 (two) and 2021 (three) publications respectively.

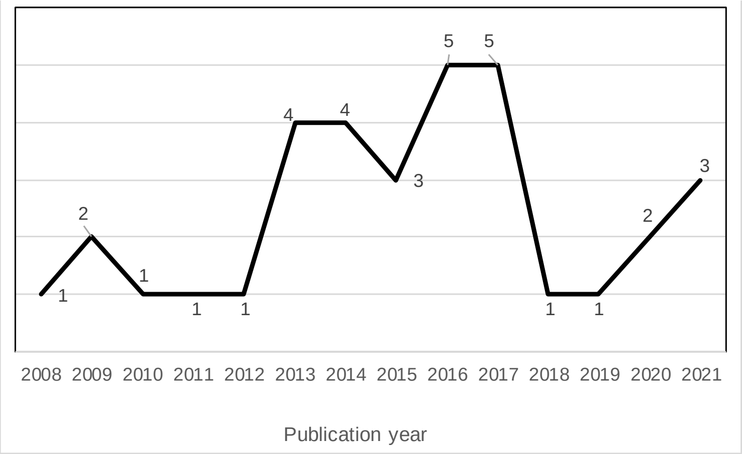


Figure 3: Number of sources per year of publication

From a source database perspective, the majority of the research papers included in the SLR (13) were retrieved from the NCBI database. This was followed by IEEE with ten sources and five from PubMed. Three sources were from ScienceDirect and Springer respectively. The number of sources from each database is illustrated in Figure 4.

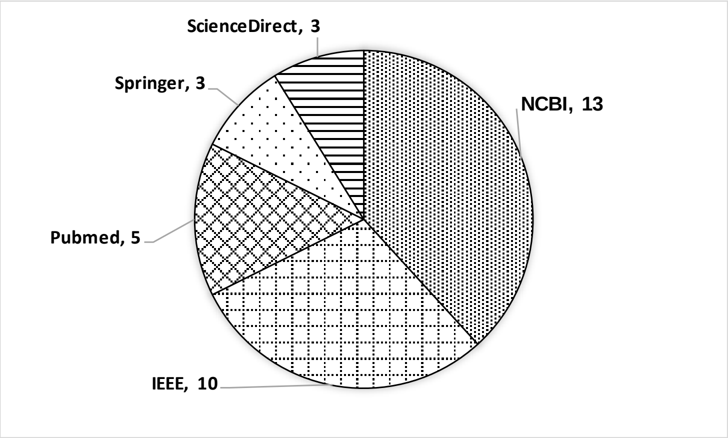


Figure 4: Number of sources per database

Analysis of research papers included in the SLR from the geographical location of the authors' perspective showed that authors from the United States accounted for nearly half of publications with 15 research papers (see Table 1). This was followed by authors from Australia and China, with four papers respectively. Two research papers were published by authors from Greece, Netherlands, United Kingdom, and Portugal respectively, while authors from Germany, Israel and Poland published one paper each. Based on the geographical location of the authors, all the research papers included in the SLR were published by researchers from developed countries in the United States and Eurasia, with none from any African country.

Country	Publication count
Australia	4
China	4
Germany	1
Israel	1
Greece	2
Netherlands	2
Poland	1
Portugal	2
United Kingdom	2
United States	15
Total	34

Table 1: Publication count by authors' country

The qualitative analysis of the sources included in the SLR entailed the following four steps:

- Full text reading of the 34 sources that met the QA criteria;
- Identification of HSNs concepts that were relevant to answering the research question;
- Grouping of similar concepts into sub-themes;
- Categorizing the sub-themes into main themes.

This process resulted in the identification of three main themes, namely provision of health information, social support, and negative consequences. The three themes are discussed in the following sub-sections.

3.1 Provision of Health Information

Johnson (1997), cited in McKinley and Wright (2014), defines health information seeking as the deliberate search for information from a specific information source(s) to guide health-related decision making. The use of the internet in general, and HSNs in particular, to search for health information is increasing (Amante et al., 2015; Lefebvre & Bornkessel, 2013; Zhao et al., 2021; Zhao & Zhang, 2017).

The motivation for using HSNs to seek information differs among the different users of these platforms (Zhou et al., 2018). Those with chronic diseases or unhealthy lifestyle behavior (e.g. smoking) often turn to HSNs to connect with people with similar conditions to share information that could support the self-management of their diseases (Frost & Massagli, 2008; Griffiths et al., 2015; Vassilev et al., 2014; Ventola, 2014). Family members and caregivers also use HSNs to access information that could empower them to support the persons they are caring for (Kamalpour et al., 2021). However, healthcare professionals are generally reluctant to use HSN platforms for direct patient care (Ventola, 2014), though recent studies have shown that some are beginning to use HSNs to communicate with their patients, answer their questions and provide general education on public health issues (Moorhead et al., 2013; Zhou et al., 2018).

Individuals that have just been diagnosed with a disease often have a strong need for information about their disease and the different treatment strategies that are available (Smailhodzic et al., 2016). HSN platforms are generally used by these patients to seek advice from "fellow sufferers" on the different treatment options that are available (Armstrong & Powell, 2009; Smailhodzic et al., 2016). Knowing what other people have gone through empowers such patients with knowledge of what to expect from their treatment.

In addition to seeking advice on treatment options, HSNs are also used by patients to ask questions about their diseases from those with similar conditions and healthcare professionals (Ventola, 2014).

HSNs provide the platform to share individual experiences, informal therapies, and personal success stories, thereby building the confidence of other patients (Johnston et al., 2013). Patients can connect with individuals with similar conditions on HSNs and capitalize on the collective wisdom of a "community of like-minded" to access information about different treatment options for their conditions as well as information about healthcare institutions with specialized healthcare professionals (Johnston et al., 2013).

3.2 Social Support

Health social support entails the exchange of resources by two or more people to improve the well-being of the recipient (Li & Yan, 2020). Social support plays a crucial role in our ability as human beings to maintain good physical and mental health (Utz & Breuer, 2017; Yao et al., 2015). Social support has been identified as an important social influence on health behaviors (Latkin & Knowlton, 2015). More specifically, HSNs contributes to behavioral change by increasing the social capital of users (Utz & Breuer, 2017). One of the key roles of social networks, i.e. the web of social links that surround an individual, is the provision of social support (Li & Yan, 2020). The network's connection reflects the people who are connected in society and how these people get support from their environment. An essential foundation for forming and maintaining social interactions is the exchange of social support (Kelly et al., 2017).

Several studies have reported on the potential positive impact that social support, facilitated through HSNs, has on behavioral change. In a study that investigated the use of FatSecret, an HSN site where users can record their dietary intake and calories burnt, Ma et al. (2010) found that with support from their online connections, users with similar weight and similar weight-change goals were more likely to lose weight when their friends do, compared to those whose friends were not making much progress. In another SLR study, Maher et al. (2014) found that nine out of the ten studies included in their review reported significant improvement in health behaviour (e.g. diet/weight loss and increased physical activity) when online social network-based interventions were incorporated into treatment strategies. Similarly, Laranjo et al. (2015) reported that health interventions that incorporate social network support appeared to be effective in promoting health behavior changes. Studies by authors like Phua (2013), found that the perceived social support from HSNs specifically designed to support people who want to quit smoking (e.g. WhyQuit) had a significant influence on members' level of smoking cessation self-efficacy, while Cheung et al. (2017) found that people who participate in online social groups can benefit from social support through information sharing, which prevented them from returning to smoking.

3.3 Negative Consequences of Health Social Network Sites

Despite the potential positive impact of HSNs on health and healthcare, healthcare professionals have not fully embraced their usage. One of the main concerns of healthcare professionals about the use of HSNs by patients is the quality of health information that is shared on these platforms

(Venkatesan et al., 2013; Ventola, 2014). Increasing use of online social networks in general, and HSNs in particular has created a space for the dissemination of false and inaccurate information (Zhao et al., 2021). This can be attributed to the fact that the discussions on HSNs are often not moderated. This can encourage the propagation and re-enforcement of health misinformation (Zhao et al., 2021). The spread of inaccurate health information on HSNs can lead to complications or fatal outcomes for users (Venkatesan et al., 2013), especially when people share drug and dosage information. A potential consequence of health misinformation is that it could create the false impression that there is no consensus on a health topic or that an official source of information cannot be trusted. This could lead to confusion or indifference among citizens (Chou et al., 2020). For example, Kricorian et al. (2021) found that people that have been exposed to misinformation about the Coronavirus and Covid-19 vaccine were more likely to be reluctant to get the vaccine.

Healthcare professionals also have the perception that the use of HSNs can impact their relationship with patients negatively. In a study by Rupert et al. (2014), participants reported that some doctors felt disempowered and marginalized when they share information obtained on HSNs with their physicians. The participants also reported that healthcare professionals do not approve their use of HSNs to seek information, with some discouraging future use because they were of the view that people posting information on HSNs do not have clinical training.

The use of HSNs to share personal health information also create concerns over the privacy and confidentiality of this information (Lefebvre & Bornkessel, 2013). For example, HSNs, such as PatientsLikeMe, actively encourage users to share their health information. Although there is no subscription fee for patients using this platform, the website generates its revenue mainly through the sale of anonymized aggregate data that are generated from patients' contributions (Kotsilieris et al., 2017). The collection and sale of personal health data to entities with commercial interests can make users vulnerable to security threats (intentional and unintentional) and the negative impacts of such threats (Kotsilieris et al., 2017).

4 Conclusion

This paper presents the results of the SLR of 34 research papers on the benefits and drawbacks of using HSNs for healthcare. The results of the analysis showed that the highest number of papers were retrieved from databases that publish eHealth-related research papers, namely NCBI (38%), IEEE (29%), and PubMed (15%). Sources from ScienceDirect and Springer were at 9% respectively. All the 34 papers included in the SLR were published by authors from developed countries, with the majority from the USA. None of the authors was from developing countries, including Africa. This highlights a gap in studies that focus on the use of HSNs for healthcare by authors from developing countries. The qualitative analysis process identified two broad benefits of HSNs, namely provision of health information and social support. The drawbacks identified include the dissemination of health misinformation, feeling of marginalization by healthcare professionals and concerns over privacy and confidentiality of health information.

One of the limitations of the study is that the search and extraction of sources were based on specific key phrases that include health social networks and healthcare. This meant that papers that could potentially have been relevant were excluded from the study because they did not use our search phrases in their keywords. Secondly, the study focused specifically on the benefits and drawbacks of HSNs in healthcare. Research papers that focused on the use of social media, in general, were excluded from the study. The inclusion of such papers could have increased the number of the themes identified in this study.

This paper contributes to the number of studies that focus on the use of HSNs to support healthcare. Given the increasing trend in the use of HSNs across the globe and the limited number of studies from developing countries that focus on this topic, more research should be done to better understand their use and impact from a developing country perspective. The continuing growth in the number of users of social media platforms creates a unique opportunity for African researchers in particular to investigate the extent to which this growth can be leveraged to address the shortage of healthcare professionals in the continent through the use of HSNs.

The study also has implications for healthcare professionals who need to play a more active role on HSNs and harness their clinical skills in the moderation of health information and online discussions to maximise the potential benefits, while minimising their possible negative consequences. With healthcare delivery evolving from the traditional paternalistic approach to one where patients actively participate in the decision-making process for their treatment, it will be difficult for healthcare professionals to sustain their resistance to the active use of HSNs by their patients.

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